



National Institutes of Health

Advisory Committee to the Director Working Group on Diversity

Subgroup on Individuals with Disabilities

REPORT

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Preface

The Advisory Committee to the Director Working Group on Diversity (ACD WGD) presents this report for consideration. It represents the deliberations of a group of subject matter experts who were recruited to serve on the ad hoc Disabilities Subgroup of the ACD WGD. As noted in the report, the group's initial charge was to 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 Subgroup quickly noted that in order to effectively address their charge, they needed to expand their focus to include research focused on addressing the health and health care disparities affecting people with disabilities and increasing the inclusion of people with disabilities in research studies. After a year of intensive deliberations, they have developed an excellent set of suggestions for consideration.

It should be noted that their efforts were not without barriers. A major barrier is the lack of comprehensive and reliable data. There are varying definitions of disability, limiting the feasibility of direct comparisons among studies. There is not consistent nor broad enough gathering of data regarding disabilities to allow comprehensive assessment of opportunities and gaps for research and enhancement of the scientific workforce.

The report discusses disability issues broadly, not limiting considerations to the areas covered by extant law. This is to be applauded, given the need articulated for more careful focus on people with disabilities.

We look forward to the next steps following receipt of this report.

Sincerely,

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Acronyms

ACD	Advisory Committee to the Director
ACS	American Community Survey
ADA	Americans with Disabilities Act
ADAAA	Americans with Disabilities Act Amendments Act
AHRQ	Agency for Healthcare Research and Quality
COSWD	Chief Officer for Scientific Workforce Diversity
DEC	Disability Engagement Committee
DEIA	Diversity, Equity, Inclusion, and Accessibility
DPCPSI	Division of Program Coordination, Planning, and Strategic Initiatives
EDI	Office of Equity, Diversity, and Inclusion
EO	Executive Order
FOA	Funding Opportunity Announcement
HBCU	Historically Black College or University
HHS	United States Department of Health and Human Services
ICs	Institutes and Centers
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities

OHR	Office of Human Resources
ORWH	Office of Research on Women's Health
PCORI	Patient-Centered Outcomes Research Institute
SGMRO	Sexual and Gender Minority Research Office
TCU	Tribal College or University
THRO	Tribal Health Research Office
WHO	World Health Organization
WGD	Working Group on Diversity

Executive Summary

People with disabilities represent more than 27% of the United States adult population, making them the single largest minority group in the country. Despite laws that prohibit discrimination against and promote inclusion of disabled people in all aspects of society, people with disabilities experience many inequities, including in employment, education, income, social determinants of health, and health care. People with disabilities are profoundly underrepresented in the biomedical and behavioral research workforce. Pervasive barriers such as ableism (i.e., the belief that people with disabilities are flawed and less valuable than nondisabled people), bias, and lack of accessible accommodations prevent people with disabilities from participating fully in the scientific workforce. Few data about people with disabilities in the biomedical and behavioral research workforce exist, yet those data demonstrate the magnitude of the underrepresentation. Interventions to promote equity and inclusion would yield needed data to describe and address the experiences, barriers, and access of diverse individuals across a broad range of disabilities and their representation in the scientific workforce across a variety of scientific disciplines.

The National Institutes of Health (NIH) is committed to promoting diversity and recently has launched major diversity and inclusion initiatives to support historically underrepresented groups. However, disabled people have not been a focus of these initiatives. This report presents suggestions from the Advisory Committee to the Director (ACD) Working Group on Diversity (WGD) [Subgroup on Individuals with Disabilities](#) about how the NIH can support the inclusion of people with disabilities in the scientific workforce and in the research enterprise. The Subgroup suggests that the NIH:

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 people with disabilities 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 individuals with disabilities
7. Conduct research on disability health and health care disparities and equity by:
 - a. Formally designating people with disabilities as a health disparity population
 - b. Funding and promoting research on health and health care disparities experienced by people with disabilities
 - 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 and anti-ableism are core components of all NIH diversity, equity, inclusion, and accessibility (DEIA) efforts
9. Maintain accountability for disability inclusion efforts

Charge of the Subgroup on Individuals with Disabilities

The [Subgroup on Individuals with Disabilities](#) is charged with supporting the Advisory Committee to the Director (ACD) Working Group on Diversity (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. 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 Subgroup intends to capture this information in a whitepaper along with detailed proposed suggestions for how the NIH might bolster its efforts to support individuals with disabilities in biomedical research. The whitepaper and proposed suggestions will be submitted to the ACD WGD and, in turn, to the ACD for review and approval.

Introduction

One in four adults in the United States has a disability.¹ Disabilities are diverse; they can be congenital, arise suddenly, or progress over time. Some people's disabilities are apparent to other people; other disabilities are invisible. Disabilities can be associated with mobility, vision, hearing, communication, intellect, learning, thinking, memory, mental health, or chronic health conditions. Some people have multiple disabilities.

For almost 50 years, federal mandates, notably [Section 504 of the Rehabilitation Act of 1973](#) and the [Americans with Disabilities Act \(ADA\) of 1990](#), have prohibited discrimination on the basis of disability. Among other things, this means that programs and services must be accessible to and usable by people with disabilities and they must provide equal opportunity to participate and benefit from public and private programs and services. Moreover, employers cannot exclude individuals with disabilities who can perform essential job functions and must provide reasonable accommodations for disabled people. Under Section 504, federal executive agencies and organizations that receive federal funding, including NIH-supported scientific research and training programs at postsecondary institutions, cannot discriminate against disabled people. Although the law was enacted nearly 50 years ago, people with disabilities remain underrepresented in the scientific research workforce. People with disabilities represent approximately 9% of the scientific workforce and less than 2% of NIH-funded principal investigators, despite being more than 27% of the United States adult population.²⁻⁴ In 2019, the unemployment rate among scientists and engineers with a disability (5.27%) was higher than the national unemployment rate (3.70%).² Additional disability prevalence data are included in Appendix A, but there is still much work needed to understand disability representation in the scientific workforce.

In recent years, the NIH and academic institutions have initiated efforts to enhance diversity and inclusion across the biomedical and behavioral research workforce, primarily to address the

underrepresentation of women, and racial and ethnic minorities. Although people with disabilities are also underrepresented in the biomedical and behavioral research workforce and are identified as a group of interest in the [Notice of NIH's Interest in Diversity](#), they have been largely excluded from these diversity and inclusion efforts. Based on anecdotal evidence from the biomedical and behavioral research workforce, diversity training often excludes disability topics, recruitment and retention efforts for disabled scientists are largely nonexistent, experts in disability and people with the lived experience of disability are often not involved, and misconceptions about how to accommodate people with disabilities remain.⁵ Thus, barriers preventing or impeding people with disabilities from entering and succeeding in scientific careers also remain. Furthermore, a lack of acceptance of and valuing people with disabilities as productive scientists undermines the goal of achieving a truly diverse and inclusive biomedical research enterprise.

The Current NIH Context

The NIH recognizes the importance of diversity in the biomedical and behavioral research workforce and founded the [Chief Officer for Scientific Workforce Diversity \(COSWD\)](#) office in 2014 in support of this recognition. In addition, the ACD WGD, a permanent working group of the ACD, was formed in 2013 and is charged with providing regular input to the ACD, which in turn advises the NIH Director on effective strategies to enhance diversity and access. The ACD WGD Subgroup on Individuals with Disabilities was established in August 2021 and charged with proposing detailed and actionable suggestions to support the inclusion of individuals with disabilities in the scientific workforce and presenting these suggestions in a report developed over the course of one year. The Subgroup's efforts will guide the ACD WGD and, in turn, inform the ACD's advice to the NIH Director about how the NIH can improve its practices and policies to better support the inclusion of disabled people and lead by example to make the biomedical and behavioral research workforce more equitable and inclusive. Although developed with input from ex-officio NIH staff who are subject matter experts in this area, this report may not fully reflect new and upcoming NIH initiatives that support accessibility and disability inclusion.

The Subgroup on Individuals with Disabilities is charged with understanding the challenges confronting disabled people in the biomedical and behavioral research workforce, based on information from peer-reviewed publications and personal stories from people with disabilities. The Subgroup is also charged with identifying strategies for the NIH to overcome these challenges, including best practices for collecting data from disabled researchers by career stage or disability type and examples of programs that have successfully supported the inclusion of people with disabilities.

Once the Subgroup began its work, the members modified their original charge to address several issues. First, there is very little peer-reviewed literature focused on disabled people in the biomedical and behavioral research workforce. Second, the Subgroup had limited time and resources to systematically collect personal stories; instead, they used their collective expertise and lived experiences related to disabilities to inform their suggestions for promoting disability inclusion. Finally, based on overwhelming feedback from the Subgroup, the initial scope of the group's work was broadened to include suggesting policy changes that lead to the expansion of research focused on addressing the health and health care disparities affecting people with disabilities and increased inclusion of people with disabilities in research studies. This broader scope recognizes that the NIH cannot increase the inclusion of people with disabilities in the biomedical and behavioral research workforce in isolation. Identifying and addressing systemic and structural factors that may contribute to the exclusion of people

with disabilities from the scientific workforce and from research, including accessibility and attitudinal barriers about people with disabilities, is necessary. These efforts will require a mindset and culture shift, which is particularly challenging given the primacy of the medical model of disability, which dates back to the founding of the NIH (as reflected in its current mission statement) and is used across biomedical research more generally.

The Subgroup also notes that formal acceptance of disability as a health disparity population under [Section 464z-3\(d\) of the Public Health Service Act, 42 U.S.C. 285t\(d\)](#), is integral to increasing both the inclusion of people with disabilities in research studies and the representation of researchers with disabilities. Including people with disabilities within the scientific workforce and in research studies will increase the evidence base for identifying and eliminating barriers to equitable health and health care for people with disabilities and enhance efforts to engage disability communities as key partners or collaborators and participants in these studies. Although it is important to recognize that the lived experiences of researchers with disabilities will provide unique insights and lead to targeted research about equitable health and health care, researchers with disabilities should not be limited to focusing on these research topics; similarly, nondisabled researchers should pursue these research topics and engage with disability communities to find ways to promote equity in health and health care. Not only are there laws prohibiting discrimination based on disability, but it is also the collective responsibility of the biomedical and behavioral research workforce to strengthen the understanding of—and develop strategies to address—societal barriers affecting the health and careers of people with disabilities.

Core Concepts

[An Introduction to Disability](#)

Disability is a multifaceted concept that is more than a physical or mental condition or diagnosis. Definitions of disability differ by purpose. For example, the definition used by the Social Security Administration to determine disability entitlement for income support programs differs from the definition used for civil rights protections under Section 504 of the Rehabilitation Act and the ADA, as amended by the [ADA Amendments Act \(ADAAA\)](#). The ADAAA was passed to ensure that the term “disability” was interpreted broadly. A 2018 review found that the United States Code, the compilation of federal statutes, defines disability in 67 places, with approximately 35 of these definitions differing in some way from one another.⁶

Two main models of disability exist. The medical model views disability as a disease or impairment that can be “corrected” through treatment.^{7,8} By contrast, the social model of disability focuses on how ableist and discriminatory attitudes, physical environments, and other barriers inhibit people with disabilities from fully participating in society.^{7,8} The social model regards disability as a human rights issue that societies must address, rather than as a failure of individuals.⁵

In developing its 2001 International Classification of Functioning, Disability, and Health, the World Health Organization (WHO) integrated these two models into a biopsychosocial-ecological definition of disability.^{8,9} WHO’s definition views “disability” as an umbrella term that accounts for the interactions between health conditions (e.g., diseases, disorders, injuries) and contextual factors, including environmental (e.g., social and structural barriers) and personal factors (e.g., age, gender, social background). As an umbrella term, this biopsychosocial-ecological definition applies in different ways in different contexts and is therefore an inclusive definition, spanning both medical and social model

concepts.⁹ Because of this broad perspective, the Subgroup used the WHO definition of disability to guide its deliberations.

Table B1 in Appendix B lists additional definitions of disability, including the federal definition of “targeted disability,” which receives special emphasis in targeted recruitment programs.¹⁰ Table B1 also contains definitions for other key terms.¹¹ Overall, the inclusive nature of the WHO definition of disability applies to the suggestions presented in this report, since all facets of disability need to be considered when providing resources to support the inclusion of people with disabilities in the scientific workforce and in research studies.

Language and Usage

Language choices affect perceptions of disability. Disability language is continually evolving based on changing societal perceptions of disability and the lived experiences of disabled people. Historically, the language used to indicate disability conveyed bias or discriminatory attitudes. Ableism is the belief that people with disabilities are flawed and less valuable than nondisabled people.¹² Like other forms of discrimination, these beliefs are deeply embedded in our society and often generate unconscious or implicit biases. Ableist language can increase stigma and exclusion of people with disabilities.¹³ Language used in the past, such as “special needs,” “differently-abled,” “handicapped,” and “mentally or physically challenged,” is today often viewed as derogatory.¹³ Other commonly used phrases (e.g., “I’m so OCD,” “what a lame excuse,” “falling on deaf ears,” “the blind leading the blind”) minimize or make light of disabilities.^{13,14} Table B2 in Appendix B outlines other examples of ableist language and organizational and structural ableism.

This report aims to use inclusive, appropriate language to describe people with disabilities. Several academic organizations and the [NIH](#) recommend using person-first language (e.g., “people with disabilities”) to reduce stigma and combat negative attitudes toward people with disabilities.⁷ According to some disability activists and researchers, however, the construction of the term “person with disabilities” dissociates the disability from the person, giving it a negative connotation. In contrast, identity-first language (e.g., “disabled people”) aims to promote individuals’ autonomy and agency.⁷ Since disability language preferences vary, the report uses person-first and identity-first language interchangeably to be inclusive of different perspectives.

Disabled People Experience Health and Health Care Disparities

As recognized by the *Healthy People* initiatives for 2010, 2020, and 2030, people with disabilities experience health and health care disparities.^{15–19} As part of its work, the Subgroup identified reports of health and health care disparities experienced by different populations of disabled individuals; that information is presented in Appendix C. The Subgroup focused exclusively on studies funded by the NIH or the Agency for Healthcare Research and Quality (AHRQ). Although Appendix C is not intended as an exhaustive list, evidence suggests that there are significant disparities for disabled people in screening and preventive services, cancer diagnosis and treatment, rates of comorbid health conditions and health risk factors, pregnancy and reproductive health and health care, communication with clinicians and satisfaction with care, physical and financial access to care, and other health conditions and needs. In addition, NIH-funded research documents discriminatory and ableist attitudes among physicians toward patients with disabilities.

Despite this evidence, neither the NIH nor AHRQ has recognized people with disabilities as a population that experiences health and health care disparities.¹⁵ In the Public Health Service Act, a population is defined as a health disparity population if there is “a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.”²⁰ Under this law, populations can be designated as a health disparity population by the Director of the National Institute on Minority Health and Health Disparities (NIMHD) after consultation with the Director of AHRQ. Since the establishment of this authority through the [Minority Health and Health Disparities Research and Education Act of 2000, P.L. 106-525](#), the NIH has identified several health disparity populations, including racial and ethnic minority populations, less-privileged socioeconomic status populations, underserved rural populations, sexual and gender minorities, and any subpopulations that can be characterized by two or more of these descriptions.²¹ In its February 2022 *Health Equity Framework*, the National Council on Disability called for the NIH and AHRQ to identify disabled people as a health disparity population.^{22,23} This Subgroup report will highlight the need to designate people with disabilities as a health disparity population, engage various disability communities in health disparities research, and increase disability representation in the biomedical and behavioral research workforce more broadly.

Limitations Faced by Disabled Researchers

People with disabilities face many institutional barriers that impede their ability to fully participate and contribute to the scientific workforce. Many aspects of scientific research are inaccessible for disabled researchers, including laboratory facilities, research instruments, meeting or conference events, and publication or computing platforms.^{24–27} Researchers with invisible disabilities often do not disclose their disability for fear of discrimination, and therefore may not receive necessary accommodations.²⁸ Some disabled people face additional bias, discrimination, and harassment due to intersectional underrepresented identities, such as disabled racial and ethnic minorities and disabled sexual and gender minorities.^{29,30} People with disabilities at Historically Black Colleges and Universities (HBCUs), Tribal Colleges and Universities (TCUs), and other Minority-Serving Institutions (MSIs) experience additional barriers in the areas of research skill building (e.g., methods and grant writing) and infrastructure (e.g., institutional review board and sponsored programs) that prevent them from participating optimally in the scientific workforce.^{31,32}

Although these barriers impede the inclusion of disabled scientists in the research enterprise, they are also a detriment to the progress of scientific research. Researchers with disabilities have unique perspectives and knowledge to contribute. Their representation and inclusion in the scientific workforce can lead to new scientific questions and discoveries that can improve health and well-being for all. Disabled investigators may also be able to leverage their trusted position in disability communities to engage members to participate in research studies that they otherwise might distrust or hesitate to join.

Intersectionality

Intersectionality is the concept that multiple social identities need to be considered to understand power, privilege, and discrimination.³³ These identities can include race, ethnicity, sexual orientation, gender identity, religion, and disability. Many experts agree that intersectional identities of people with disabilities need to be considered to fully address discrimination and biases in different aspects of society, such as health care access, employment, and financial stability. Research suggests that specific intersectional identities, including being female, being older, belonging to a marginalized racial group,

and having a behavioral disability, put people at higher risk for disability-related harassment.³⁴ There are also systemic and institutional biases that discount intersectional identities. For example, professional and academic organizations largely do not include Asians and Asian Americans as an underrepresented minority in the scientific and medical workforce.³⁵ Although Asians and Asian Americans have high representation in the scientific workforce overall, they are not well represented in leadership roles, so researchers who identify as Asian and disabled may be hindered in ways that are currently not tracked.

As the NIH considers the suggestions from this report, it is important that the NIH also consider implementing a research agenda that closely examines the roles that intersectionality plays in terms of representation in the scientific workforce among people with disabilities who are also members of marginalized racial, ethnic, gender identity, and sexual orientation groups. The NIH should also ensure that people with disabilities are included in ongoing efforts to collect data on intersectionality.

Universal Design

Under the principles of universal design, all environments, policies, and procedures are designed in a way that maximizes access for everyone.^{36,37} Often, changes made to improve access for people with disabilities also facilitate the lives of nondisabled people. Some classic examples are curb cuts, which accommodate wheelchair users but also assist people pushing strollers or pulling shopping carts, and closed captioning, which accommodates some people who are deaf or hard of hearing but is also useful to other people in noisy environments. The NIH should assess whether certain accommodations, particularly changes forced by the COVID-19 pandemic, might benefit not only people with disabilities but also others. One example is convening meetings and grant review sessions by remote videoconferencing, which may facilitate broader inclusion of people from across many underrepresented groups.³⁸⁻⁴⁰ During the pandemic, NIH grant application study sections were virtual without obvious negative effects on the quality of the reviews. The NIH could hold all study sections through remote videoconferencing, which would facilitate participation by people with disabilities who have difficulty traveling and spare nondisabled members the inconvenience of travel while also saving on hotel and travel expenses and facilitating participation from experts worldwide. However, these virtual options must prioritize accessibility to be effective, and principles of universal design should guide all future activities at the NIH.

The ACD WGD Subgroup on Individuals with Disabilities' Suggestions to Support the Inclusion of Disabled People in the Scientific Workforce

The Subgroup recognizes that programs and policies that use disability status or other demographic variables for decision making must be implemented in compliance with applicable law. Creating reasonable accommodations or reasonable modifications for physical accessibility, providing effective communication, and creating space for greater inclusion of people with disabilities will require thoughtful approaches that engage people with disabilities. In alignment with [Executive Order \(EO\) 13985](#), the NIH must implement targeted interventions to foster an inclusive and equitable workforce. The Subgroup supports efforts at the NIH to comply with EO 13985 and advance inclusion of disabled people in all intramural and extramural activities.

Update the NIH Mission Statement

One immediate action for the NIH to support disability inclusion is to remove the language of “reducing disability” from the NIH mission statement. The current mission statement could be interpreted as

perpetuating ableist beliefs that disabled people are flawed and need to be “fixed” (Appendix B). The NIH should revise the mission statement to be, “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.”

Establish an NIH Office of Disability Research

Over the years, the NIH has created Offices to coordinate research activities involving specific populations and address issues within the scientific workforce. Some Offices, such as the [Office of Research on Women’s Health \(ORWH\)](#), have been congressionally mandated; others, including the [Sexual and Gender Minority Research Office \(SGMRO\)](#) and the [Tribal Health Research Office \(THRO\)](#), have been formed to better coordinate policies, programs, and research activities affecting these specific populations.

In parallel with these efforts, the NIH should create an Office of Disability Research, with the mission of advancing inclusion of disabled people in research, as both investigators and research participants, and to advance disability-related research. Achieving these goals will require collaboration with other NIH offices and institutes and centers (ICs). In addition, addressing disability-related concerns requires specialized expertise and an understanding of the lived experience of disability. This Office would promote representation of researchers with disabilities at all career levels, including in NIH-supported training programs. It should also oversee efforts to increase the inclusion of people with disabilities in research projects as human subjects through collaboration with the NIH Office of Extramural Research and the NIH Intramural Research Program.

Creating an Office of Disability Research is a critical step toward fostering an equitable, inclusive workforce for people with disabilities. The Subgroup recognizes that forming a new office would require sufficient and significant resources, strategic planning, and potential restructuring—although centralizing some activities, such as access accommodations, may create economies of scale. There are currently several NIH Offices and initiatives that support disability-related issues, but this decentralized strategy has several major limitations. First, there is no single unified home for coordinating disability-related research activities, resulting in limited oversight of disability research needs and gaps, as well as silos in disability research. Second, there is no centralized, coordinated effort to lead NIH-wide culture and process changes. Although the [Office of Equity, Diversity, and Inclusion \(EDI\)](#) has led several campaigns to enhance disability awareness and promote the availability of resources, EDI’s focus is on the NIH workforce, leaving gaps in these efforts for the broader biomedical and behavioral research workforce. Moreover, EDI’s efforts are hindered by limitations in staff and financial resources dedicated to disability inclusion efforts.

To better understand the resources needed to create the Office of Disability Research, the Subgroup suggests that the NIH take immediate action to reassess the existing disability inclusion and disability research infrastructure at the NIH. This effort should also involve the examination of all available quantitative and qualitative data sources needed to make progress outlined in this report.

The Office of Disability Research should be modeled after other successful NIH-wide offices for specific populations, including the ORWH, SGMRO, and THRO. Similar to these offices, the Office of Disability Research should be integrated into the [Division of Program Coordination, Planning, and Strategic Initiatives \(DPCPSI\)](#) within the Office of the Director (OD). The Office of Disability Research staff should

represent diverse perspectives from disability communities, including people with disabilities and experts in disability inclusion, research, and equity. Importantly, the Office of Disability Research should be equipped with sufficient resources, support, and authority to allow this Office to be the responsible party or have critical input on the suggestions presented in this report.

In order to accomplish its mission, the primary objectives of the Office of Disability Research should include:

- Advising the NIH Director and staff on issues related to disability research, which differs from funding research on diseases, pathophysiological mechanisms, and health conditions that can cause disability
- Strengthening and enhancing research related to issues and areas of health and health equity that affect populations with disabilities, including studies involving specific types of disabilities
- Ensuring that NIH-supported research addresses issues related to people with disabilities, their health, and their health and health care equity and advances rigorous research relevant to the health and health care equity of disabled people as a group
- Developing opportunities to support recruitment, retention, reentry, and advancement of people with disabilities in biomedical careers
- Collecting and reporting data on the representation and inclusion of people with disabilities in the biomedical and behavioral research workforce
- Increasing the representation of people with disabilities as research participants
- Ensuring that all NIH-funded research accounts for disability as a demographic variable
- Promoting inclusion of disabled people as research partners or collaborators and on research advisory bodies
- Researching approaches to maximize the accessibility and integrate principles of universal design of all NIH facilities, communication, publications, and events

The Office of Disability Research would lead efforts to enhance disability representation in the workforce and scientific research, as noted above, and these efforts should be implemented in close collaboration with ICs as well as other NIH entities that have relevant statutory requirements and those that overlap in scope (e.g., EDI, COSWD, Office of Human Resources [OHR]). The Office of Disability Research should also partner with other offices at the NIH and across the federal government to improve disability representation. Some of these collaborations could include:

- Providing resources and technical assistance to NIH staff to expand accessibility and implement universal design in all facets at the NIH
- Sharing research findings with EDI and other partners or collaborators as appropriate
- Working with the COSWD, EDI, and OHR offices at the NIH to support the inclusion of people with disabilities in all DEIA efforts and programs
- Contributing to federal disability research initiatives and policies by participating in the federal [Interagency Committee on Disability Research \(ICDR\)](#), along with other NIH entities that are already engaged, to align the NIH with other such initiatives

Establish an NIH Disability Equity and Access Coordinating Committee

Currently, EDI manages a [Disability Engagement Committee \(DEC\)](#), which works with the Principal Strategist for the People with Disabilities Employment Portfolio to recommend strategies to eliminate

barriers to the employment, promotion, and advancement of individuals with disabilities and promote inclusion and accessibility for all NIH staff. The DEC is composed of internal subject matter experts across the NIH. Although these efforts are important, the NIH should create an NIH Disability Equity and Access Coordinating Committee that serves as a resource to the Office of Disability Research, acts as a representative of different disability communities, and involves both DEC members and external experts to increase disability representation in the scientific workforce and all phases of research. The committee should have a well-defined scope that complements the work of the DEC.

One important task for the Disability Equity and Access Coordinating Committee should be to solicit input from various disability advocacy and community-based groups and provide feedback to the Office of Disability Research about all office activities, notably training initiatives and data that the NIH should collect about disability. The committee should address how to define and inquire about disability identity, how best to gather data about disability, and about how to report information about disability among NIH awardees, trainees, staff, and research participants. The committee should also propose changes or additions to existing safeguards intended to protect intramural and NIH-funded researchers, trainees, and research participants from discrimination and harassment based on disability disclosure.

Other responsibilities of this committee should include:

- Serving as a resource to the Office of Disability Research, COSWD, EDI, and other pertinent offices
- Suggesting strategies for training and anti-ableism initiatives within the NIH
- Monitoring progress on the NIH's implementation strategies and providing recommendations for enhancing these strategies over time, based on input from people with disabilities, disability inclusion experts, and other partners or collaborators from disability communities

Develop an NIH-Wide Effort to Identify and Address Any Structural Ableism That May Exist and Promote Disability Inclusion

The NIH has made many efforts in recent years to identify and address potential barriers—such as [sexual harassment](#) and [structural racism](#)—to promote a diverse and equitable scientific workforce. The NIH should take the same approach to address potential structural ableism and promote disability inclusion. These efforts should be supported by NIH leadership and led by the Office of Disability Research (or the interim responsible party) in consultation with the Disability Equity and Access Coordinating Committee and should focus on:

- Supporting equity for and inclusion and excellence of people with disabilities in the NIH culture and structure
- Promoting disability inclusion and anti-ableism through training, communication, policy, accessibility, and accountability
- Reviewing policy, culture, and structure to identify opportunities to promote disability inclusion in the NIH-funded research workforce
- Understanding perspectives from different disability communities and partners or collaborators
- Obtaining data on disability in intramural and extramural activities to support and monitor disability inclusion efforts
- Conducting research on health disparities and health equity of different disability communities

Foster Support for the Equity, Inclusion, and Belonging for People with Disabilities Within the NIH's Culture and Structure

To comply with EO 13985 and achieve meaningful and lasting change in the NIH's support for the inclusion of people with disabilities, cultural and structural changes must occur. With advice from the Disability Equity and Access Coordinating Committee, these changes should be implemented with input from disability inclusion experts, partners or collaborators from various disability communities, and disabled individuals with lived experience as members of NIH committees and panels. People with disabilities of all types should be represented on all NIH leadership teams, grant review panels, and advisory committees, including the ACD, the ACD WGD, and the Council of Councils. The NIH should also establish an anti-ableism steering committee, which would be analogous with the NIH's Anti-Racism Steering Committee (ARSC), to monitor and continue to build upon the progress that could be made based on suggestions in this report.

Another important step in creating cultural and structural change is commitments from ICs for equity for and inclusion of disabled people. Similar to the IC-specific Racial and Ethnic Equity Plans (REEPs), ICs should develop and enact Disability Equity, Inclusion, and Accessibility Plans. These plans should identify disparities and establish goals for improving equity for people with disabilities in each IC's workforce, structure, and systems. These plans should also permit audits to ensure progress in meeting IC-specific goals, and efforts should be made to ensure consistency across IC-specific policies and approaches.

As part of these efforts to improve equity for and inclusion of disabled people, the NIH should generate reliable and publicly available data that indicate whether the goals of these plans are being met. Data should also indicate the disability representation of the NIH staff and NIH trainees. Although [EDI is tracking these data](#), it is necessary to expand data collection beyond physical and cognitive disabilities classified as targeted disabilities.¹⁰ The NIH should collect more granular data about disability representation (e.g., types of disabilities, disabled staff and trainees' roles, salaries, career level) to provide a clearer understanding of disparities and guide strategies for promoting equity and inclusion. Appendix A provides more detailed suggestions about how the NIH should collect these types of data.

Advance Disability Inclusion and Anti-Ableism Through Training, Communication, Policies, and Accessibility

Ableism is pervasive in our society, as is discrimination against disabled people.⁴¹⁻⁴⁴ To follow all aspects of EO 13985 and promote inclusion of people with disabilities in the scientific workforce, the NIH should combat ableism by using a multipronged approach informed by the Disability Equity and Access Coordinating Committee that includes training, communications and policies, and full accessibility.

Training

The NIH should develop and track the completion and impact of mandatory training for the NIH workforce—including intramural and extramural staff, support staff, and contractors—and study section members to address explicit and implicit ableism. Although the NIH has implemented implicit bias education efforts across the entire workforce and through the Center for Scientific Review, [the current version of this training](#) does not include a focus on disability or exercises related to ableism. These anti-ableism training programs should include but not be limited to a focus on hiring, retaining, and promoting NIH staff and should be evaluated and monitored over time.

Communications and Policies

A vital step for the NIH to promote inclusion of disabled people is to identify and remove any ableist language and images that may exist in its communication and policy practices. As noted above, the NIH should immediately remove the language of “reducing disability” from its mission statement. Following this action, the NIH should review all ICs’ mission statements to identify and address any ableist undertones that may exist. The Subgroup encourages the NIH to consider leveraging this opportunity to address the importance of diversity more broadly in its mission statements.

In addition to removing any ableist language that may exist in mission statements, the NIH should undertake organization-wide efforts to identify and remove any ableist language and images that may exist in current policies, programs, and communications. Lessons learned from the partners or collaborators involved in updating the mission statements can be applied to these efforts. Through this process, the NIH can develop policies that guard against ableist language and support the use of disability inclusive images in policies, programs, and communications.

The NIH should also establish itself as an inclusive institution for people with disabilities through its communications. NIH leadership should strongly support these activities, which should be shepherded by a central entity that is accountable for their successful completion. Some potential initiatives the NIH should undertake include:

- Continually recognizing and promoting anti-ableism and disability inclusion through various NIH communication channels, such as the Open Mike Blog and the COSWD Blog
- Creating new guidelines to ensure that language used in Funding Opportunity Announcements (FOAs) is disability-inclusive and culturally appropriate
- Developing and implementing resources, mandatory staff training, and policies focused on disability-inclusive language across the NIH through existing communications offices
- Developing systems and strategies to ensure consistency across IC disability-related policies and procedures
- Providing effective communication to individuals with disabilities, including staff, consultants, advisory committee members and members of the public, and others, and ensuring that grantees receiving federal financial assistance from NIH do the same

Full Accessibility

Another aspect of ableism involves inaccessible communication and physical spaces. Inadequate accessible services, facilities, transportation, and other activities pose barriers, lead to exclusion, act as a form of discrimination, and are not compliant with legal requirements. Currently, the Department of Justice is working on establishing rules to develop regulations on website accessibility that is applicable to recipients of federal financial funds. This highlights the need for compliance with Section 508 of the Rehabilitation Act and to address inadequate information technology and electronic accessibility.⁴⁵ Although EDI is charged with addressing issues of accessibility, additional responsibility lies within the NIH Office of Management. Efforts to address communication and physical accessibility across all NIH campuses and among NIH-funded institutions should aim to increase the urgency or prioritization necessary to support true inclusion.

One solution to address physical and communication accessibility at the NIH is to create and provide sufficient support for an NIH-wide group to oversee accessibility support and standardize approaches

across the NIH and in intramural research spaces by working in close collaboration with EDI, the Office of Management, the Office of Research Services, the Center for Information Technology, and other relevant groups across the NIH. This group would work similarly to how information technology security is managed at the NIH by monitoring issues and providing support for ensuring physical and communication access. Universal design and accessibility principles promulgated by the NIH should be employed and monitored at all NIH-funded institutions.

As part of their monitoring process, this accessibility oversight group would conduct audits of physical and communication accessibility of all NIH and NIH-funded digital and physical spaces. The digital spaces would include virtual meetings and events (e.g., NIH VideoCast), public and internal webpages, FOAs, virtual announcements, blogs, and other communication modalities. The physical spaces would include conference facilities, meeting spaces, transportation (e.g., shuttle buses), laboratories, offices, and all Clinical Center spaces, including on-site facilities for lodging patients and other visitors. The accessibility oversight group would share the results of the audits through public reports at least annually and set priorities for improving access that include budgets for accomplishing these priorities. In addition, this accessibility group would collaborate with disabled staff, researchers, and other disability community members to identify and create improvement plans for physical and communication accessibility gaps and support universal design approaches in NIH and NIH-funded physical and digital spaces.

The Subgroup recognizes that the NIH is in the process of hiring a Section 508 program manager with experience and expertise in accessibility/Section 508 information and communication technologies to lead the NIH Section 508 program. The Section 508 program manager will serve as a subject matter expert regarding information technology and technology systems, as well as adopting best practices and working closely with the NIH ICs' Section 508 coordinators to ensure full compliance with accessibility across the NIH. Although this is a critical improvement, it is imperative that the Section 508 coordinator be equipped with sufficient dedicated staff and funding to effectively lead and monitor NIH's Section 508 program. Importantly, the scope of the proposed accessibility oversight group should expand beyond compliance with Section 508. It is important to recognize that compliance with Section 504 and Section 508 is the minimum requirement to support accessibility. The NIH can and should go beyond these legal obligations to foster a culture that is inclusive of people with disabilities. Thus, the NIH should significantly amplify its approach to ensuring that communication and physical spaces are welcoming, comfortable, and safe to use and navigate, in collaboration with people with disabilities.

The NIH should also examine any barriers to reasonable accommodations that may exist at the NIH or at NIH-funded institutions through systematic assessments. This examination may include collecting information on the use of indirect costs to support reasonable accommodations at NIH-funded institutions.

Review Policy, Culture, and Structure to Identify Opportunities to Promote Disability Inclusion in the NIH-Funded Research Workforce

As the world's premier scientific research agency, the NIH can lead by example in its efforts to enhance disability inclusion, but it can also enact initiatives and policies to promote disability inclusion in the NIH-funded research workforce. There is limited evidence about successful practices and programs that support the inclusion of people with disabilities throughout their career paths in the biomedical and behavioral research workforce, mostly because very few programs have been thoroughly evaluated.⁴⁶

The NIH should collect and use data to develop evidence-based strategies to improve training,

mentorship, access, infrastructure and other resources to support the inclusion of people with disabilities in the NIH-funded workforce. Resources should be allocated to evaluate the effectiveness of interventions over time. Additional details about the Subgroup's suggestions for improved data collection are outlined in Appendix A.

The NIH should also use the following strategies to promote disability inclusion:

- Pilot intramural and extramural cohorts and programs that facilitate networking, access, and advancement of careers to support the success of people with disabilities at all career stages, including trainees and early-career researchers.
- Use targeted funding opportunities to support the research, development, and implementation of strategies to improve accommodations, promote disability inclusion, and combat ableism in the scientific workforce.
- Promote the inclusion of disabled researchers in training programs, networking events, and informational activities by collecting disability representation data, tracking the metrics of success, and reporting these data annually.
- Participate in disability-related deliberations of the White House's Equitable Data Working Group.

Expand Efforts to Include Disability Communities and the Perspectives of Individuals with Disabilities

When addressing cultural issues or challenges facing a specific population, the NIH has endeavored to engage with experts, partners or collaborators, and members of various communities to better understand their perspectives. For example, as part of its UNITE initiative, the NIH conducted [more than a dozen sessions](#) with internal and external partners or collaborators to seek their views on issues that hinder progress toward equity for and inclusion of racial and ethnic minorities.

With guidance from the Disability Equity and Access Coordinating Committee, the NIH can take a similar approach by engaging people with disabilities and disability partners or collaborators to understand the factors that may perpetuate structural ableism and ways to improve equity, inclusion, and access to support the inclusion of disabled people at the NIH and in the external scientific community. This can be done through facilitated and accessible sessions led by people with expertise in disability inclusion that explicitly engage people with diverse disabilities. There should also be specific efforts to understand unique challenges experienced by disabled people with intersectional identities and at different types of institutions, including HBCUs, TCUs, and Hispanic-Serving Institutions (HSIs). Strategies should include communications with NIH staff and external researchers, including key informants (e.g., researchers who self-identify as being disabled), and Requests for Information (RFIs) that inform policy to increase disability cultural competency, combat ableism, and bolster disability inclusion internally at the NIH and externally at research institutions.

In addition to these strategies, the NIH should gather systematic information about disabled researchers' experiences with the NIH grant application and review processes. These data should go beyond anecdotal evidence and capture quantifiable information about disabled researchers' interactions with NIH extramural program officers, the electronic information system, and the grant application submission systems. These data can also be used to understand whether the researchers'

applications were discussed and/or funded and whether the researchers chose to resubmit to the NIH or other research funders.

The Subgroup recognizes that NIH leadership has already begun to open the lines of communication with disabled people and disability partners or collaborators via sessions to gather information and other forums in support of the NIH DEIA Strategic Plan, prepared in accordance with [Report 116-450 on H.R. 7614](#) and [EO 14035](#). Although these efforts represent important progress, a larger coordinated effort is needed to ensure that the disability community continues to have input on NIH policies, procedures, and initiatives. It is critical that those leading or moderating these efforts have specific expertise in issues affecting different disability communities. Moreover, targeted outreach should seek input from people representing different disability types.

Conduct Research on Disability Health and Health Care Disparities and Equity

A growing body of research—including studies funded by the NIH and AHRQ (Appendix C)—has identified health and health care disparities affecting people across disability groups. However, much remains to be done to fully understand the extent of these disparities, the factors that contribute to inequitable health and health care, and how to improve health and outcomes in partnership with people with disabilities. To address these issues, the NIH should commit to funding and promoting disability-related health disparities research, improving collection of data about people with disabilities, and supporting inclusion of people with disabilities as research participants.

Formally Designating People with Disabilities as a Health Disparity Population

Importantly, as noted above, the Subgroup suggests that people with disabilities should be formally designated as a health disparity population under Section 464z-3(d) of the Public Health Service Act, 42 U.S.C. 285t(d). The research evidence presented in Appendix C includes only studies funded by the NIH and AHRQ and is not meant to be exhaustive. This appendix shows a convenience sample of NIH-funded and AHRQ-funded studies relating to health and health care disparities for disabled people, including research from various NIH institutes, centers, and offices, such as the National Center for Medical Rehabilitation Research at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. Alongside research funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR); the Centers for Disease Control and Prevention (CDC); the Health Resources and Services Administration (HRSA); the Assistant Secretary for Planning and Evaluation (ASPE) in the United States Department of Health and Human Services (HHS); the Patient-Centered Outcomes Research Institute (PCORI); and other federal agencies, nonprofits, and private philanthropies, this rigorous and extensive research confirms that people with disabilities meet the law's requirements for identification as a health disparity population. Recognition by the NIH and AHRQ as a health disparity population is foundational to increasing both the representation of researchers with disabilities and the inclusion of people with disabilities in research studies. Including scientists with the lived experience of disability will enhance the quality of the research needed to identify and eliminate barriers to equitable health care experienced by people with disabilities and bolster efforts to engage disability communities in these studies.

The Subgroup acknowledges that NIMHD is having conversations with the Administration for Community Living (ACL), AHRQ, and others about whether they should consider this designation. The Subgroup suggests that these current efforts and collaborations should be expedited, leveraging the abundance of existing research evidence.

Funding and Promoting Research on Health Disparities Experienced by People with Disabilities

After officially identifying people with disabilities as a health disparity population, the NIH should commit to funding research that addresses the inequities experienced by people with disabilities. Furthermore, the NIH should commit to transparency, accountability, and sustainability of these research efforts by analyzing grant applications and award data to find any structural or institutional barriers that lead to underfunding health disparities research related to people with disabilities. The first step for this type of analysis is to create a [Research, Condition, and Disease Categorization \(RCDC\)](#) for disability. This analysis should also include a yearly review of grant applications and awarded research related to disability health disparities to address any needed improvements in these research efforts.

Collecting Data on Disability Wherever Demographic Information Is Collected Within NIH Data Systems

Comprehensive data collection is another important aspect to fully understanding health and health care disparities that affect disabled people. The NIH should commit to improved data collection, analysis, and dissemination of disability data both in the general public and in the scientific workforce. As part of the efforts to collect data on disabled people in the scientific workforce, the NIH should collaborate with partners at the HHS to learn about the best practices for gathering and reporting disability data (Appendix A). By aligning with other HHS components, the NIH can learn how the experiences of people with disabilities at the NIH compare with the experiences of other disabled people across HHS.

Supporting Inclusion of Disabled People as Research Participants

People with disabilities are often excluded from or not actively recruited as participants in research.⁴⁷ In order to maximize the inclusion of people with disability in research, NIH ICs should be encouraged to review and adopt [the community engagement requirements](#) that are used by other research institutions, such as NIDILRR and PCORI. With input from the Disability Equity and Access Coordinating Committee, disability community partners or collaborators should be involved in research topic development, analysis, and interpretation of research findings to ensure that this research is impactful and moves the field forward. These disability community partners or collaborators should also support the application of the latest research through appointments on NIH advisory committees and other federal advisory committees. In addition, the NIH should share accessible lay articles and research publications on disability-related topics across its communication platforms.

Ensure Disability Inclusion and Anti-Ableism Are Core Components of All NIH DEIA Efforts

The NIH has devoted resources to identify and address structural issues in the scientific workforce through DEIA initiatives. Although these DEIA efforts address many structural issues, such as racism and sexual harassment, the NIH should ensure that disability inclusion and anti-ableism are basic elements of all DEIA programs, initiatives, policies, and funding opportunities. Additionally, consistent with EO 13985, any communication and messaging about DEIA at the NIH should include language about disability.

COSWD and EDI are major drivers of DEIA efforts at the NIH. The NIH could take different approaches to ensure that disability inclusion and anti-ableism are part of COSWD and EDI activities. First, the NIH should appoint a senior advisor to COSWD and the EDI Director who can ensure that disability inclusion and anti-ableism are addressed in all DEIA programs, initiatives, and policies. This senior advisor should be an expert in disability inclusion, equity, and research. They should also have lived experience with disability and strong connections with the various disability communities. This senior advisor should hold

a position within the Office of Disability Research, collaborate across many partners, and have access to financial resources to ensure success with their efforts to promote disability inclusion and anti-ableism.

This senior advisor could also be involved in updating [the COSWD Strategic Plan](#) to include disability in all lists of populations covered and highlighting accessibility by using definitions of terms outlined in [EO 14035](#). The COSWD Strategic Plan should also include people with disabilities in all initiatives that are meant to enhance inclusion to maximize opportunities for groups mentioned in EO 14035.

Maintain Accountability for Disability Inclusion Efforts

To be effective, all of these suggested efforts to advance disability inclusion and anti-ableism at the NIH must be monitored, and the results of these efforts should be shared publicly. Supervision and transparency around these efforts would maximize the likelihood of improving attitudes and practices at the NIH and NIH-funded institutions. As part of these accountability efforts, data should be collected on an ongoing basis and reported at least yearly on the following topics:

- Uptake and impact of NIH disability-related training (e.g., impact on accessibility and the inclusion of people with disabilities in the NIH workforce)
- Efforts and commitments to advance disability inclusion and address potential ableism in NIH communications
- Improvements in accessibility, including but not limited to transportation, physical environments, websites, and communication
- Metrics of disability inclusion and accessibility as part of the impact score of NIH grant applications, following [models](#) similar to those created by NIDILRR and PCORI
- Number and percentage of program directors/principal investigators with disabilities identified on grant applications and awards by disability types and across intersecting underrepresented groups in [the NIH Databook](#)
- Number and percentage of study section members with disabilities

Conclusions

Despite the recognition from scientific programs and institutions like the NIH of the importance of DEIA, people with disabilities continue to experience discrimination, lack of representation, and other barriers to fully participating and succeeding in the scientific workforce. Taking the actions suggested by ACD WGD Subgroup on Individuals with Disabilities can help the NIH meet and exceed legal standards to guard against disability discrimination, enhance the culture, and be model stewards in partnership with people with disabilities. Overall, these suggestions require the NIH to engage with diverse disability communities, address potential structural ableism and discrimination, promote awareness among nondisabled members of the scientific community, and include disability perspectives in all DEIA discussions and activities. People with disabilities should be included in the NIH's efforts to address racism and harassment, since disabled people with intersectional identities are more likely to experience bias and discrimination. As the NIH commits to addressing and improving the inclusion of disabled people in the scientific workforce and research studies, the perspectives and participation of people with disabilities will be represented. This can lead to research studies and research teams that more accurately reflect the makeup and address the needs of the United States population, enhancing the NIH's ability to achieve its mission.

References

1. Disability and Health Promotion. Disability and Health Overview. Centers for Disease Control and Prevention. September 16, 2020.
<https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>
2. National Center for Science and Engineering Statistics, National Science Foundation. *Women, Minorities, and Persons with Disabilities in Science and Engineering*. April 29, 2021.
<https://nces.nsf.gov/pubs/nsf21321/>
3. 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.
4. Varadaraj V, Deal JA, Campanile J, Reed NS, Swenor BK. National prevalence of disability and disability types among adults in the U.S., 2019. *JAMA Netw Open*. 2021;4(10):e2130358.
5. Gordián-Vélez WJ. Ensuring the inclusion of people with disabilities in STEM education and careers. *JSPG*. 2022;20(2).
6. New Editions Consulting Inc. *Federal Statutory Definitions of Disability*. 2018.
7. Dunn DS, Andrews EE. Person-first and identity-first language: developing psychologists' cultural competence using disability language. *Am Psychol*. 2015;70(3):255–264.
8. World Health Organization. *Towards a Common Language for Functioning, Disability and Health: The International Classification of Functioning, Disability, and Health*. 2002.
9. Stineman MG, Streim JE. The biopsychological paradigm: a foundational theory for medicine. *PM R*. 2010;2(11):1035–1045.
10. U.S. Equal Employment Opportunity Commission. *Questions & Answers: Promoting Employment of Individuals with Disabilities in the Federal Workforce*. 2008.
<https://www.eeoc.gov/laws/guidance/questions-answers-promoting-employment-individuals-disabilities-federal-workforce>
11. Iezzoni LI, Freedman VA. Turning the disability tide: the importance of definitions. *JAMA*. 2008;299(3):332–334.
12. Villines Z. What is ableism, and what is its impact? *Medical News Today*. November 7, 2021.
<https://www.medicalnewstoday.com/articles/ableism>
13. Andrews EE, Powell RM, Ayers K. The evolution of disability language: choosing terms to describe disability. *Disabil Health J*. 2022;15(3):101328.
14. Andrews EE, Forber-Pratt AJ, Mona LR, Lund EM, Pilarski CR, Balter R. #SaytheWord: a disability culture commentary on the erasure of “disability.” *Rehabil Psychol*. 2019;64(2):111–118.
15. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an underrecognized health disparity population. *Am J Public Health*. 2015;105 Suppl 1(Suppl 2):S198–S206.
16. Iezzoni LI. Eliminating health and health care disparities among the growing population of people with disabilities. *Health Aff (Millwood)*. 2011;30(10):1947–1954.
17. National Center for Health Statistics. *Healthy People 2000 Final Review*. 2001.
18. National Center for Health Statistics. *Healthy People 2010 Final Review*. 2011.
19. National Center for Health Statistics. *Healthy People 2020 Final Review*. 2021.
20. Public Health Service Act, 285t(d) §464z-3(d). 2022.
21. National Institute on Minority Health and Health Disparities. Minority Health and Health Disparities: Definitions and Parameters. <https://www.nimhd.nih.gov/about/strategic-plan/nih-strategic-plan-definitions-and-parameters.html>
22. National Council on Disability. NCD Letter to NIMHD, AHRQ Regarding Health Disparity Population Designation for People with Disabilities. <https://ncd.gov/publications/2021/ncd-letter-nimhd-ahrq-health-disparity-population-designation>

23. National Council on Disability. *Health Equity Framework for People with Disabilities*. 2022.
24. Editorial. Disability shouldn't limit accessibility in science. *Commun Biol*. 2021;4(1):895.
25. Wu Y-H, Martiniello N, Swenor BK. Building a more accessible conference for researchers with vision impairment. *JAMA Ophthalmol*. 2021;140(2):113–114.
26. Ramp J, Parker CG, Rhodes JS, Malik P. Barriers to inclusion: service dog handlers in science laboratories. *Disabil Health J*. 2021;14(3):101070.
27. Jeannis H, Joseph J, Goldberg M, Seelman K, Schmeler M, Cooper RA. Full-participation of students with physical disabilities in science and engineering laboratories. *Disabil Rehabil Assist Technol*. 2018;13(2):186–193.
28. Yerbury JJ, Yerbury RM. Disabled in academia: to be or not to be, that is the question. *Trends Neurosci*. 2021;44:507–509.
29. Powell K. Academia's ableist culture laid bare. *Nature*. October 4, 2021 2021;(598):221–223.
30. Cech EA. The intersectional privilege of white able-bodied heterosexual men in STEM. *Sci Adv*. 2022;8(24):eabo1558.
31. Moore CL, Manyibe EO, Aref F, Washington AL. Research capacity building: a historically black college/university-based case study of a peer-to-peer mentor research team model. *Rehabilitation Research, Policy, and Education*. 2017;31(3):283–308.
32. Moore CL, Manyibe EO, Sanders P, Aref F, Washington AL, Robertson CY. A disability and health institutional research capacity building and infrastructure model evaluation: a tribal college-based case study. *Rehabilitation Research, Policy, and Education*. 2017;31(3):309–336.
33. Crenshaw K. *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1st Ed. Chicago: University of Chicago Legal Forum; 1989.
34. Shaw LR, Chan F, McMahon BT. Intersectionality and disability harassment: the interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin*. 2012;55(2):82–91.
35. Ogunyemi D. Unique Populations. <https://www.aamc.org/professional-development/affinity-groups/gfa/unique-populations>
36. Reich C, Price J, Rubin E, Steiner M. *Inclusion, Disabilities, and Informal Science Learning. A CAISE Inquiry Group Report*. Washington, DC: Center for Advancement of Informal Science Education; 2010.
37. Gallaudet University. DeafSpace. <https://gallaudet.edu/campus-design-facilities/campus-design-and-planning/deafspace/>
38. Skiles M, Yang E, Reshef O, Muñoz DR, Cintron D, Lind ML, et al. Conference demographics and footprint changed by virtual platforms. *Nature Sustainability*. 2021;5:149–156.
39. Wu J, Rajesh A, Huang YN, Chhugani K, Acharya R, Peng K, et al. Virtual meetings promise to eliminate geographical and administrative barriers and increase accessibility, diversity and inclusivity. *Nature Biotechnol*. 2022;40(1):133–137.
40. Sarabipour S, Khan A, Seah Y, Mwakilili AD, Mumoki FN, Sáez PJ, et al. Changing scientific meetings for the better. *Nat Hum Behav*. 2021;5(3):296–300.
41. Nario-Redmond MR. *Ableism: The Causes and Consequences of Disability Prejudice*. Wiley-Blackwell; 2019.
42. Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agarannik ND, Donelan K, et al. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297–306.
43. Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agarannik ND, Lagu T, et al. U.S. physicians' knowledge about the Americans with Disabilities Act and accommodation of patients with disability. *Health Aff (Millwood)*. 2022;41(1):96–104.

44. Meeks LM, Conrad SS, Nouri Z, Moreland CJ, Hu X, Dill MJ. Patient and coworker mistreatment of physicians with disabilities. *Health Aff (Millwood)*. 2022;41(10):1396–1402.
45. U.S. Department of Justice Civil Rights Division. Guidance on Web Accessibility and the ADA. <https://beta.ada.gov/resources/web-guidance/>
46. Dahlberg ML, Byars-Winston A, eds. *The Science of Effective Mentorship in STEMM*. National Academies of Sciences, Engineering, and Medicine; 2019.
47. DeCormier Plosky W, Ne’eman A, Silverman BC, Strauss DH, Francis LP, Stein MA, Bierer BE. Excluding people with disabilities from clinical research: eligibility criteria lack clarity and justification. *Health Aff (Millwood)*. 2022;41(10):1423–1432.

Appendix A: Disability Data

Currently, few data are publicly available about disability prevalence in the National Institutes of Health (NIH) internal and external research workforce or the participation of disabled people in NIH-funded studies. The Subgroup suggests that NIH should collect disability data in all places that gather age, gender, race, and ethnicity data and include disability data as part of any demographic data it reports. This also includes intersectional data on disability and data by institution type (e.g., Minority-Serving institutions [MSIs]).

The goal of an NIH disability data collection effort would be to identify, monitor, and address barriers to disability inclusion in the biomedical and behavioral research workforce and among participants in research studies. Although there are many approaches for gathering disability data, data collection methods should be (1) consistent with those used in other United States Department of Health and Human Services (HHS) agencies to allow comparisons, (2) selected in partnership with the disability community, and (3) able to support data comparisons over time and across biomedical and behavioral research workforce diversity efforts.

Appendix A provides data on disability prevalence and evidence on the exclusion of people with disabilities from science, technology, engineering, and mathematics (STEM) education and the biomedical and behavioral research workforce. This summary supports the need for an NIH-wide effort to combat potential ableism and increase disability inclusion in science and research.

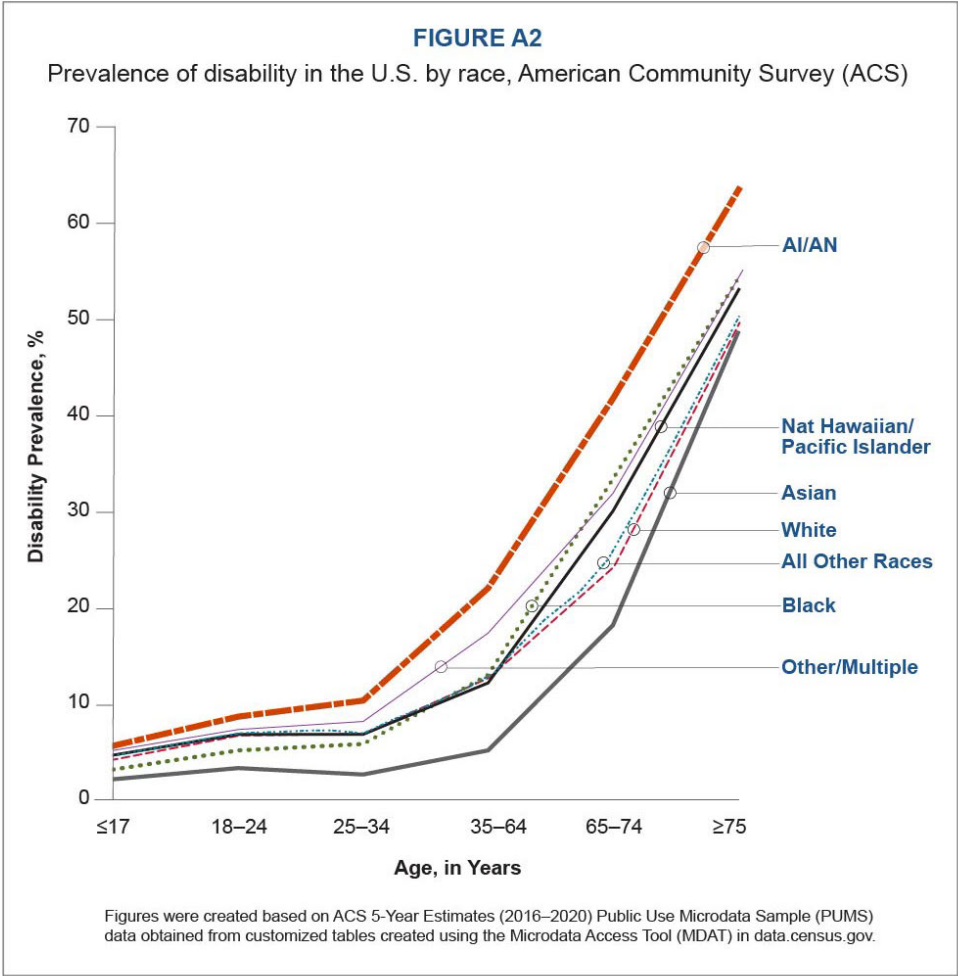
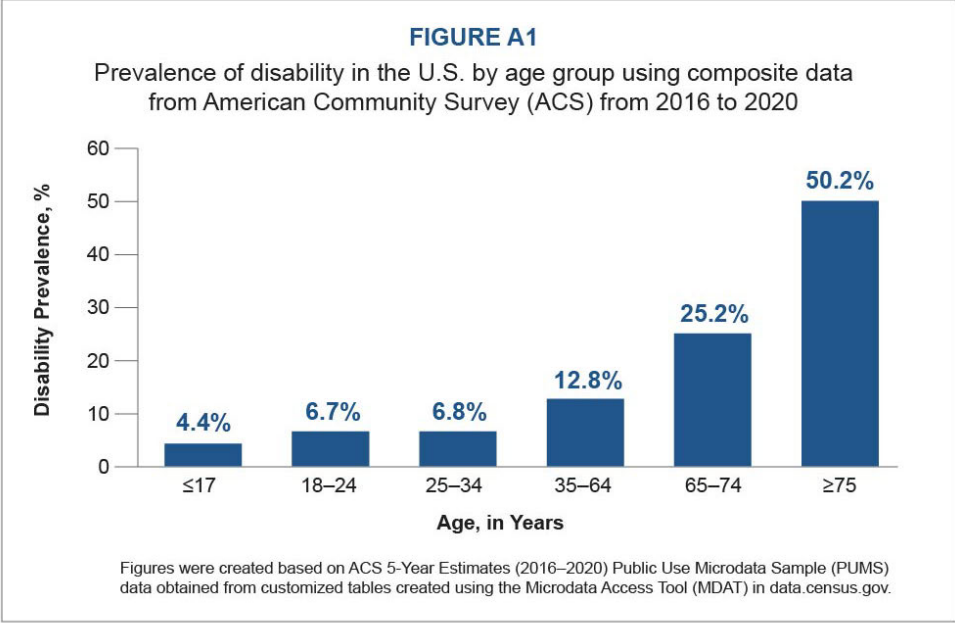
Disability Prevalence

People with disabilities comprise the largest minority population in the United States. In 2016, there were 61 million disabled American adults, representing 26% of the United States population.¹ This prevalence increased by 2019, when more than 67 million United States adults, or 27%, had a disability.¹ Over the next decade, the disability community is expected to grow exponentially due to the COVID-19 pandemic and population aging.

Disability prevalence differs by age and race.

Disability prevalence increases with age. The prevalence of disability among children (17 years and under) is 4.4%, but it increases to more than half (50.2%) of adults 75 years old and older (Figure A1). Although the highest disability rates occur at older ages, disabilities are also 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.

The prevalence of people with disabilities varies by racial groups. Across all ages, disability prevalence is highest among American Indians and Alaskan Natives (Figure A2). Approximately 6% of children 17 years and under and 63.6% of adults 75 years and older who identify as American Indian or Alaskan Native have a disability. Disability prevalence is lowest among people who identify as Asian, with 2.2% of children 17 years and under and 48.9% of adults 75 years old and older reporting disabilities.



Data on People with Disabilities in the Biomedical and Behavioral Research Workforce

People with disabilities are underrepresented in the scientific workforce.

Over the past decade, less than 2% of NIH- and National Science Foundation (NSF)–funded principal investigators reported having a disability.^{2,3} Although 27% of American adults have disabilities, data from the *Women, Minorities, and Persons with Disabilities in Science and Engineering 2021* report indicate that only 19% of undergraduate students reported a disability. Beyond undergrad, disability representation in the scientific workforce decreases.⁴ Only 9% of doctoral students and 8% of postdoctoral students in science and engineering report a disability.⁴ The representation of faculty with disabilities does not improve as 8% of assistant professors and 10% of associate and full professors in science, engineering, or health fields report disability. Slightly less than 5% of medical students and approximately 3% of practicing physicians report disability.^{5,6} Academic leadership is also dismal—8% of department directors, chairs, and chancellors report a disability, and similarly, 8% of university presidents and provosts have a disability.

Although some may interpret these statistics as disabled people’s lack of interest in scientific careers, barriers to inclusion and lack of institutional support could be discouraging people with disabilities from pursuing a career in science. For example, the [University of Washington’s Center for Sensorimotor Neural Engineering](#) implemented many activities and practices to promote the inclusion of disabled people at all career levels. These practices included highlighting achievements of people with disabilities, recruiting and engaging with disabled students and faculty, providing accommodations, and many others that are aligned with the suggestions in this report. As a result of these efforts, disability representation among undergraduate students, graduate students, faculty, and leadership is significantly higher compared to all Engineering Research Centers.⁷ These results indicate that people with disabilities are interested and capable of pursuing careers in science, but institutions need to make focused efforts to demonstrate that they will be supported and included as equitable members of the research workforce.

Researchers with disabilities are underrepresented in NIH funding.

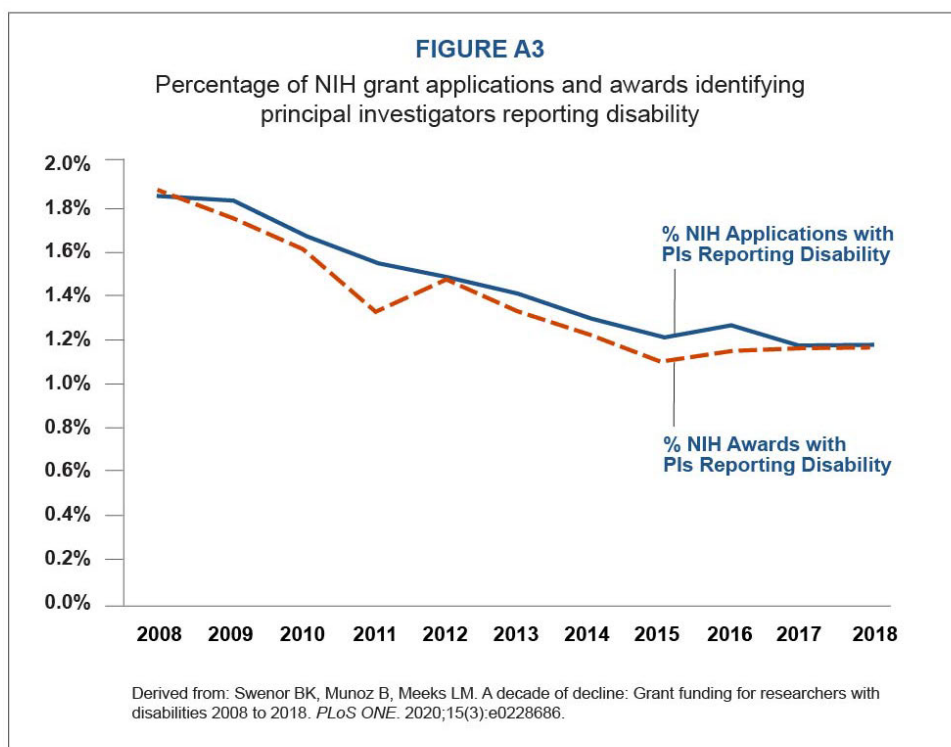
Between 2008 and 2018, the percentage of NIH grant awards with a principal investigator reporting disability significantly declined from 1.9% to 1.2% (Figure A3).² Over this period, grant success rates were also significantly lower for applications identifying principal investigators reporting disability, with 27.2% of applications identifying principal investigators reporting disability being awarded funding, compared with 29.7% of applications identifying principal investigators not reporting disabilities. Importantly, in fiscal year 2018, only 34 out of more than 1,100 applications for diversity supplements indicated they were supporting disabled researchers, representing only 3% of all diversity supplements received that year.⁸ Overall, limited data are collected to determine the potential for inequities among NIH-funded researchers with disabilities.

Although there is a lack of intersectional data, there are hints that people with disabilities with identities that intersect with other marginalized groups (e.g., racial/ethnic minorities) could be further underrepresented as NIH-funded researchers. For example, white researchers are significantly more likely than Black and Hispanic researchers to be supported by NIH grants.^{9,10} American Indians and Alaskan Natives, who have the highest disability prevalence compared to other racial groups, served as principal investigators on only 114 research grants in 2021, compared to 28,780 white principal investigators.¹¹ Disability and racial/ethnic data suggest that disabled researchers with intersectional

marginalized identities face more barriers and are less represented as NIH-funded researchers. A broader understanding of NIH funding disparities experienced by researchers with disabilities will help ensure that those from multiple marginalized populations are included in the discourse and participate in translational programmatic solutions.

There are barriers to inclusion for people with disabilities.

In addition to data indicating underrepresentation, there is evidence of unaddressed barriers to the inclusion of people with disabilities in research and medicine. A 2019 NIH climate survey found that 29.5% of NIH employees and trainees with disabilities reported being sexually harassed in the past year, compared with 21% of respondents without disabilities.¹² Recent data from Canada found that faculty with disabilities are 1.8 times more likely to report workplace harassment than faculty without disabilities.¹³ In contrast, data indicated that female faculty are 1.5 times more likely to report harassment than male faculty.¹³



NIH Disability Data Gaps

The NIH does not require disability data reporting for research studies.

Currently, all NIH grantees must provide an annual report with data on the gender, race, ethnic group, and age of research participants. These data are used to assess the diversity of research study populations. Even though people with disabilities are the largest minority population in the United States, the NIH does not require collecting data on the inclusion of people with disabilities in research. There is evidence that the eligibility criteria outlined in many clinical trials exclude people with disabilities due to lack of clarity or scientific justification.¹⁴ Data on disability representation in research studies are necessary to assess the generalizability of the research findings, ensure that the diversity of participants reflects the population, and support efforts to address health inequities.¹⁵ To address this

issue, the NIH could add people with disabilities to the [Inclusion Policies for Research Involving Human Subjects](#).

The NIH's current efforts to collect disability data on the biomedical and behavioral research workforce are inadequate.

As noted previously, limited data are collected to determine the potential for inequities among NIH-funded researchers with disabilities. The NIH primarily gathers data on program director/principal investigator disability status through self-reporting under the eRA Commons portal's demographics section.² In this system, disability status is determined by responses to the question, "Do you have a disability?" The response options are "yes," "no," or "do not wish to provide." Researchers selecting "yes" can indicate disability type by selecting all categories that apply from among "mobility/orthopedic," "hearing," "visual," and "other." These four categories are the only disability types offered, excluding the opportunity to capture data on and create an inclusive environment for people with other types of disabilities, including learning disabilities, psychiatric disabilities, neurodiversity, and chronic conditions. Data collection should include either an open-ended question about disability or a comprehensive self-categorization of disability types, including physical/mobility, mental illness/psychiatric, sensory, developmental, neurological, intellectual/cognitive, and chronic illness to avoid underreporting.

Disability data gaps should be closed using established disability data collection approaches. There are well-established and validated questionnaires to assess disability. The NIH should review and rely on these approaches to fill current disability data gaps in research studies and the biomedical and behavioral research workforce. Below are the two most frequently used question sets to collect disability data (Table A1). However, as Table A1 outlines, there are differences between these questionnaires, although there is high agreement across instruments.¹⁶ Both sets of questions have limitations, as they do not capture data on all disability types (e.g., psychosocial disabilities, chronic health conditions).¹⁷⁻¹⁹

HHS has published a data collection standards-based disability question set.

[Section 4302 of the Affordable Care Act](#) requires the Secretary of HHS to establish data collection standards for many demographic aspects, including disability status. Section 4302 of the Affordable Care Act also contains provisions to strengthen federal data collection efforts by requiring that all national federal data collection efforts collect information on many demographic aspects, including disability status.²⁰ In response to this mandate, HHS has published guidance on disability data collection that should be implemented in all national population health surveys and for all data collection in HHS agencies and offices, including the NIH.²¹ This HHS guidance includes using a six-item questionnaire, the same disability questions included in the American Community Survey (ACS).^{21,22} In 2022, the Office of the National Coordinator for Health Information Technology also endorsed the use of these six questions and one question from the Washington Group that captures communication disabilities (Table A1) to be included in electronic health records and to support data interoperability.²³ Under the HHS guidance, the six questions, which all have yes-or-no responses, must be included as a minimum, with allowance for additional questions as needed.

The Washington Group on Disability Statistics has developed a disability question set. The Washington Group on Disability Statistics developed a set of six questions to collect data on disability.²⁴ This set of questions was developed in consultation with members of the disability community for international use by the United Nations and is used widely, including by the Centers for Disease Control and Prevention (CDC).^{24,25} These six questions are similar to the ACS set of questions but have some key differences. The Washington Group disability question set offers response options that indicate the level of difficulty: “no difficulty,” “some difficulty,” “a lot of difficulty,” and “cannot do at all.” These options provide granularity on functioning for each task, and disability is often categorized as having some or more difficulty on any one task. Additionally, the Washington Group set includes a question about communication disability, but there is not a question about independent living.

Table A1. Disability Questionnaires		
Disability	American Community Survey (ACS) Disability Questions ²²	Washington Group (WG) Disability Questions ²⁴
Hearing	Are you deaf or do you have serious difficulty hearing?	Do you have difficulty hearing even if using a hearing aid?
Seeing	Are you blind or do you have difficulty seeing, even when wearing glasses?	Do you have difficulty seeing, even if wearing glasses?
Mobility	Do you have serious difficulty walking or climbing stairs? (5 years old or older)	Do you have difficulty walking or climbing stairs?
Cognitive	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)	Do you have difficulty remembering or concentrating?
Self-Care	Do you have difficulty dressing or bathing? (5 years old or older)	Do you have difficulty with self-care such as washing all over or dressing?
Independent Living	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)	N/A
Communication	N/A	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Appendix A References

1. Varadaraj V, Deal JA, Campanile J, Reed NS, Swenor BK. National prevalence of disability and disability types among adults in the U.S., 2019. *JAMA Netw Open*. 2021;4(10):e2130358.
2. 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.
3. National Science Foundation. *Merit Review Process Fiscal Year 2019 Digest*. 2020.
4. National Center for Science and Engineering Statistics NSF. *Women, Minorities, and Persons with Disabilities in Science and Engineering*. 2021. <https://nces.nsf.gov/pubs/nsf21321/>
5. Meeks LM, Case B, Plegue M, Swenor BK. Change in prevalence of disabilities and accommodation practices among U.S. medical schools, 2016 vs. 2019. *JAMA*. 2019;322(20):2022–2024.
6. Nouri Z, Dill MJ, Conrad SS, Moreland CJ, Meeks LM. Estimated prevalence of U.S. physicians with disabilities. *JAMA Netw Open*. 2021;4(3):e211254.
7. Bellman S, Burgstahler S, Chudler EH. Broadening participation by including more individuals with disabilities in STEM: promising practices from an engineering research center. *Am Behav Sci*. 2018;62(5):645–656.
8. Lauer M. Expanding NIH’s Definition of Socio-Economic Disadvantaged to be More Inclusive and Diversify the Workforce. *Open Mike* blog. 2019. <https://nexus.od.nih.gov/all/2019/11/26/expanding-nih-definition-of-socio-economic-disadvantaged-to-be-more-inclusive-and-diversify-the-workforce/>
9. Ginther DK, Haak LL, Schaffer WT, Kington R. Are race, ethnicity, and medical school affiliation associated with NIH R01 type 1 award probability for physician investigators? *Acad Med*. 2012;87(11):1516–1524.
10. Ginther DK, Schaffer WT, Schnell J, Masimore B, Liu F, Haak LL, Kington R. Race, ethnicity, and NIH research awards. *Science*. 2011;333(6045):1015–1019.
11. National Institute of Health Research Portfolio Online Reporting Tools. *The NIH-Funded Research Workforce: Data By Race*. *NIH Data Book*. February 2022. <https://report.nih.gov/nihdatabook/category/25>
12. NIH Chief Officer of Scientific Workforce Diversity. *NIH Workplace Climate and Harassment Survey Summary Findings Report*. 2020. https://diversity.nih.gov/sites/coswd/files/images/docs/NIH_Workplace_Climate_and_Harassment_Survey_Executive_Report_508.pdf [PDF, 478 KB]
13. Canadian Association of University Teachers. *By the Numbers: Harassment Among Faculty and Researchers in Post-Secondary Institutions*. Ottawa, Canada: Canadian Association of University Teachers; 2021. <https://www.caut.ca/bulletin/2021/09/numbers-harassment-among-faculty-and-researchers-post-secondary-institutions>
14. DeCormier Plosky W, Ne’eman A, Silverman BC, Strauss DH, Francis LP, Stein MA, Bierer BE. Excluding people with disabilities from clinical research: eligibility criteria lack clarity and justification. *Health Aff (Millwood)*. 2022;41(10):1423–1432.
15. Swenor B, Deal JA. Disability inclusion as a key component of research study diversity. *N Engl J Med*. 2022;386(3):205–207.
16. Weeks JD, Dahlhamer JM, Madans JH, Maitland A. Measuring disability: an examination of differences between the Washington Group Short Set on Functioning and the American Community Survey disability questions. *National Health Statistics Reports*. 2021;(161):1–9.

17. Washington Group on Disability Statistics. *An Introduction to the Washington Group on Disability Statistics Question Sets*. Hyattsville, MD: Washington Group on Disability Statistics; 2020.
18. Hall JP, Kurth NK, Ipsen C, Myser A, Goddard K. Comparing measures of functional difficulty with self-identified disability: implications for health policy. *Health Aff (Millwood)*. 2022;41(10):1433–1441.
19. Ipsen C, Chambless C, Kurth N, McCormick S, Goe R, Hall J. Underrepresentation of adolescents with respiratory, mental health, and developmental disabilities using American Community Survey (ACS) questions. *Disabil Health J*. 2018;11(3):447–450.
20. U.S. Department of Health and Human Services, Office of Minority Health. *Improving Data Collection to Reduce Health Disparities*. https://minorityhealth.hhs.gov/assets/pdf/checked/1/Fact_Sheet_Section_4302.pdf [PDF, 31.5K]
21. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. Washington, DC: U.S. Department of Health and Human Services; 2011. <http://aspe.hhs.gov/datacncl/standards/ACA/4302>
22. United States Census Bureau. How Disability Data Are Collected from the American Community Survey. <https://www.census.gov/topics/health/disability/guidance/data-collection-ac.html>
23. Office of the National Coordinator for Health Information Technology. ONC Standards Bulletin 2022-2. https://www.healthit.gov/sites/default/files/page/2022-07/Standards_Bulletin_2022-2.pdf [PDF, 325K]
24. Washington Group on Disability Statistics. WG Short Set on Functioning (WG-SS). <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>
25. Centers for Disease Control and Prevention. Washington Group on Disability Statistics. https://www.cdc.gov/nchs/washington_group/wg_questions.htm

Appendix B: Definitions of Disability and Examples of Ableist Language and Beliefs

Table B1. Definitions of Disability

Term and Source	Definition
Disability	
The Americans with Disabilities Act (ADA) of 1990	With respect to an individual, (A) “a physical or mental impairment that substantially limits one or more of the major life activities of such individual;” (B) a record of such an impairment; or (C) being regarded as having such an impairment.
Social Security Administration	Inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.
Centers for Disease Control and Prevention (CDC)	“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).”
World Health Organization (WHO)	“Umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s function and disability...as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including social, attitudinal, and physical environments and personal attributes.
Targeted disabilities	
Rehabilitation Act of 1973	“Deafness, blindness, missing extremities, partial paralysis, complete paralysis, convulsive disorders, mental retardation,* mental illness, and distortion of limb and/or spine.”

*Although the original definition for *targeted disabilities* included this term, this language is now considered derogatory and is no longer used in language related to disabilities.

Table B2. Examples of Ableist Language and Beliefs

The internal/lived experience of disability	<ul style="list-style-type: none"> • “Whole” versus “broken” • Accepting and appreciating differences • Compassion versus pity
Reality of institutionalized ableism	
Ableist traditions	<ul style="list-style-type: none"> • Segregate to provide accommodations • Paternalism is appropriate when dealing with a disabled person • Disability = failure, the inability to cure or “fix” disabled people • Disabled people are unsightly, embarrassing, and uncomfortable for those around them; they are neither to be seen nor heard (except for super-achievers, those with inspirational stories).
Ableist beliefs	<ul style="list-style-type: none"> • People with disabilities are feeble. • People with disabilities are intellectually inferior. • People with disabilities cannot function independently. • The lives of people with disabilities have less value. • People with disabilities cannot contribute equally to the larger society (i.e., they are a net loss to society).
Ableist opinions	<ul style="list-style-type: none"> • People with disabilities have an inferior quality of life. • People with disabilities are too busy trying to manage their disease to successfully manage anything else. • Disabled people cannot speak for themselves.
Ableist myths	<ul style="list-style-type: none"> • People with disabilities cannot fully participate in all of life’s roles, responsibilities, and activities. • All disabled people want to be cured of their disabilities. • “Of course they want our pity and help!”
Reality of systemic ableism	<ul style="list-style-type: none"> • Unequitable education • Unequitable access to health care • Unequitable employment • Unequitable access to housing/residence ownership • Unequitable resources • Unequitable access/ability to accumulate personal wealth

Appendix C: Research Projects Funded by NIH and the Agency for Healthcare Research and Quality (AHRQ) That Have Identified Health and Health Care Disparities for People with Disabilities

Section 464z-3(d) of the Public Health Service Act, 42 U.S.C. 285t(d), authorizes the designation of populations as “health disparity populations” if there is “a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.” The Act gives the authority to identify “health disparity populations” to the Director of the National Institute on Minority Health and Health Disparities at the NIH, after consultation with the Director of AHRQ. People with disabilities have not yet been identified under this authority as a health disparity population.

Given this authority, this section focuses on examples of research projects funded by the NIH or AHRQ that demonstrate people with disabilities meet the Act’s definition of having health or health care disparities. Please note that Appendix C is not meant to be exhaustive—it provides selected examples of NIH- and AHRQ-funded projects organized by broad topic areas. By concentrating only on studies funded by the NIH and AHRQ, Appendix C does not include the large body of evidence documenting health and health care disparities for people with disabilities funded by the Centers for Disease Control and Prevention (CDC), the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the Health Resources and Services Administration, (HRSA), the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services, the Patient-Centered Outcomes Research Institute (PCORI), other federal agencies, and private philanthropies.

- Screening and Preventative Services (pages 38–39)
- Cancer (pages 39–42)
- Comorbid Health Conditions and Health Risk Factors, Including Obesity (pages 42–46)
- Pregnancy and Reproductive Health (pages 46–62)
- Satisfaction with Care and Communication with Clinicians (pages 62–64)
- Financial Access to Care (page 64)
- Rural Residents with Disabilities (pages 64–65)
- Barriers to Care, Failures to Accommodate Disability, and Ableist Attitudes (pages 65–66)

Screening and Preventive Services

AHRQ R01 HS10223. “Quality of Care and Service Use for Persons with Disabilities.” PI: Lisa I. Iezzoni. 1999–2002.

- Iezzoni LI, McCarthy EP, Davis RB, Harris-David L, O’Day B. Use of screening and preventive services among women with disabilities. *Am J Med Qual.* 2001;16(4):135–144.

Analyses of 1994–1995 National Health Interview Survey (NHIS), with Disability, Family Resources, and Healthy People 2000 supplements. Women with major lower extremity mobility difficulties had much lower adjusted odds of Pap tests (odds ratio = 0.6; 95% confidence interval, 0.4–0.9), mammograms (odds ratio = 0.7 [0.5–0.9]), and smoking queries (odds ratio = 0.6 [0.5–0.8]).

NIH R01 CA160286-01A1. "Examining Disparities in Cancer Screening for Persons with Disabilities." PI: Lisa I. Iezzoni. 2012--2014.

- Iezzoni LI, Kurtz SG, Rao SR. Trends in mammography over time for women with and without chronic disability. *J Women's Health*. 2015;24(7):593-601.

Analyses of National Health Interview Survey for women 50 to 74 years old from selected years between 1998 and 2010. In multivariable logistic analyses, having any difficulty with basic actions was significantly associated with lower adjusted odds of mammography; for example, adjusted odds (95% confidence interval) = 0.5 (0.3-0.8), p = 0.006 in the mobility disability model.

- Iezzoni LI, Kurtz SG, Rao SR. Trends in Pap testing over time for women with and without chronic disability. *Am J Prevent Med*. 2016;50(2):210-219.

Analyses of National Health Interview Survey responses from selected years between 1998 and 2010 from women aged 21-65 years without histories of cervical cancer or hysterectomy. In 2010, the adjusted odds ratio for reporting Pap testing for women noting the most severe movement difficulty compared with nondisabled women was 0.35 (95% confidence interval [CI], 0.15-0.79).

Cancer

NIH R01 CA100029. "Cancer Care and Its Outcomes for Disabled Medicare Patients." PI: Lisa I. Iezzoni. 2003-2007.

- McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, Iezzoni LI. Disparities in breast cancer treatment and survival for women with disabilities. *Ann Intern Med*. 2006;145:637-645.

Analyses of Surveillance, Epidemiology, and End Results (SEER) Program tumor registry data merged with Medicare data for women who received a diagnosis of stage I to IIIA breast cancer at 21 to 64 years of age from 1988 to 1999. Women with disabilities had lower rates of breast-conserving surgery than other women (43.2% vs. 49.2%; adjusted relative risk, 0.80 [95% CI, 0.76-0.84]). Among women who had breast-conserving surgery, disabled women were less likely than other women to receive radiotherapy (adjusted relative risk, 0.83 [CI, 0.77-0.90]) and axillary lymph node dissection (adjusted relative risk, 0.81 [CI, 0.74-0.90]). Women with disabilities had lower survival rates than those of other women in all-cause mortality (adjusted hazard ratio, 2.02 [CI, 1.88-2.16]) and breast cancer-specific mortality (adjusted hazard ratio, 1.31 [CI, 1.18-1.45]).

- McCarthy EP, Ngo L, Chirikos T, Roetzheim R, Li D, Drews RE, Iezzoni LI. Cancer stage at diagnosis and survival among persons with Social Security Disability Insurance on Medicare. *Health Serv Res*. 2007;42(2):611-628.

Analyses of Surveillance, Epidemiology, and End Results (SEER) Program data and SEER-Medicare linked data for 1988-1999. Persons with SSDI/Medicare experienced higher all-cause mortality for each cancer (breast, lung, colorectal, and prostate). Cancer-specific mortality was higher among disabled persons for breast and colorectal cancer patients.

- lezzoni LI, Ngo LH, Li D, Roetzheim RG, Drews RE, McCarthy EP. Treatment disparities for disabled Medicare beneficiaries with stage I non-small cell lung cancer. *Arch Phys Med Rehabil.* 2008;89(4):595–601.

Analyses of SEER data merged with Medicare data for persons ages 21 to 64 years when diagnosed with stage I, pathologically confirmed, first primary non-small cell lung cancer from 1988 to 1999. Although 82.2% of nondisabled persons had surgery, 68.5% of disabled persons received operations. Adjusted relative risks (RRs) of receiving surgery were especially low for persons with respiratory disabilities (adjusted RR = .76; 95% confidence interval [CI], .67–.85), nervous system conditions (adjusted RR = .86; 95% CI, .76–.98), and mental health and/or intellectual disabilities (adjusted RR = .92; 95% CI, .86–.99). Persons with disabilities had significantly higher cancer-specific mortality rates (hazard ratio [HR] = 1.37; 95% CI, 1.24–1.51) than persons without disabilities. Observed differences in cancer mortality persisted after adjusting for demographic and tumor characteristics (adjusted relative HR = 1.23; 95% CI, 1.10–1.39). Further adjustment for surgery use eliminated statistically significant differences in cancer mortality between persons with and without disabilities across disabling conditions.

- lezzoni LI, Ngo LH, Li D, Roetzheim RG, Drews RE, McCarthy EP. Early-stage breast cancer treatments for younger Medicare beneficiaries with different disabilities. *Health Serv Res.* 2008;43(5 Pt 1):1752–1767.

Analyses of Surveillance, Epidemiology, and End Results program data, linked with Medicare files and Social Security Administration disability group. Compared with nondisabled women, those with mental disorders and neurological conditions had significantly lower adjusted rates of breast conserving surgery and radiation therapy. Survival outcomes also varied by disability type.

NIH R21 CA122130. “Early-Stage Breast Cancer Treatment Decisions by Women with Physical Disabilities.” PI: Lisa I. lezzoni. 2006–2009.

- lezzoni LI, Kilbridge K, Park ER. Physical access barriers to care for diagnosis and treatment of breast cancer among women with mobility impairments. *Oncol Nurs Forum.* 2010;37(6):711–717.

Qualitative analyses from in-depth interviews with 20 women with chronic mobility impairments who developed early-stage breast cancer prior to age 60. The 20 participants identified inaccessible equipment, including mammography machines, examining tables, and weight scales. The patients sometimes needed to insist on being transferred to an examining table when physicians preferred to examine them seated in their wheelchairs. When staff would transfer them, patients feared injury or felt badly when clinical personnel were injured during transfers. Even when clinical sites had accessible equipment, this equipment was sometimes unavailable for the appointment.

- lezzoni LI, Park ER, Kilbridge KL. Implications of mobility impairments on the diagnosis and treatment of breast cancer. *J Women’s Health.* 2011;20(1):45–52.

Qualitative analyses from in-depth interviews with 20 women with chronic mobility impairments who developed early-stage breast cancer prior to age 60. Many women made decisions about surgical approach and chemotherapy by explicitly considering how various therapies would

affect their arms, which are essential to their mobility (they use ambulation aids, self-propel manual wheelchairs, or otherwise rely on their arms for mobility or safety). Managing at home after surgery posed major mobility challenges, especially for women who lived alone. Several women reported feeling they suffered more chemotherapy side effects than do women without mobility problems. Weight gains with endocrine therapy compromised the mobility of several women.

NIH R21 HD095240-01. "Exploring Timeliness of Cancer Diagnoses in Persons with Significant Physical Disability." PI: Lisa I. Iezzoni. 2018–2021.

- Iezzoni LI, Rao SR, Agaronnik N, El-Jawahri. Cross-sectional analysis of the association between four common cancers and disability. *J Natl Compr Canc Netw*. 2020;18(8):1031–1044.

Analyses of 2010–2017 National Health Interview Survey. Persons with preexisting disability had significantly higher rates of cancer (ranging from 0.40 [SE, 0.05] for ovarian to 3.38 [0.14] for prostate) than did those without disability (0.20 [0.02] and 1.26 [0.04] for the same cancers; all $P < .0001$). Multivariable analyses found strong associations of preexisting movement difficulties (MD) and complex activity limitations (CAL) with colorectal cancer, with adjusted odds ratios (aORs) of 1.5 (95% CI, 1.2–1.9) and 1.9 (1.5–2.4), respectively. For non-Hodgkin's lymphoma, the aOR for CAL was 1.5 (1.1–2.1). For prostate cancer, aORs for MD were 1.2 (1.0–1.3) and 1.1 (1.0–1.3) for CAL.

- Iezzoni LI, Rao S, Agaronnik ND, El-Jawahri A. Associations between disability and breast or cervical cancers, accounting for screening disparities. *Med Care*. 2021;59(2):139–147.

Analyses of 2010, 2013, 2015, and 2018 National Health Interview Surveys, which included supplemental surveys on cancer screening. Compared with women without disability, women with pre-existing movement difficulties (MD) or complex activity limitations (CAL) had significantly higher rates of breast cancer (2.2% versus 3.5% and 3.6%, respectively) and cervical cancer (0.6% versus 0.8% and 1.0%, respectively). Women with disability had significantly lower recent mammography and Pap test rates than women without disability. After adjusting for all covariates, the odds ratios (95% CIs) of pre-existing CAL for cancer diagnoses were 1.21 (1.01–1.46; $p = 0.04$) for breast cancer and 1.43 (1.04–1.99; $p = 0.03$) for cervical cancer.

- Agaronnik N, El-Jawahri A, Kirschner K, Iezzoni LI. Exploring cancer treatment experiences for patients with pre-existing mobility disability. *Am J Phys Med Rehabil*. 2021;100(2):113–119.

In-depth interviews with 20 participants with preexisting mobility disability, subsequently diagnosed with cancer (excluding skin cancers). Concerns coalesced around 4 themes: disability-related healthcare experiences affect cancer treatment decisions, concerns about cancer treatment worsening functional impairments, access barriers, and limited provider awareness and biases about treating people with disability. Participants raised concerns that their underlying disability may be used to justify less aggressive treatment. Inaccessible hospital rooms, lack of accessible medical equipment, and attitudinal barriers complicated treatments.

- Agaronnik N, El-Jawahri A, Lindvall C, Iezzoni LI. Exploring the process of cancer care for patients with pre-existing mobility disability. *JCO Oncol Pract*. 2021;17(1):e53–e61.

Analyses of electronic health records of 27 patients with pre-existing chronic mobility impairment who were newly diagnosed with one of three common cancers (colorectal, prostate, and non-Hodgkin lymphoma) between 2005 and 2017. Clinicians' notations coalesced around four major themes: (1) patients' health risks raise concerns about diagnostic processes; (2) cancer signs or symptoms can be erroneously attributed to the patient's underlying disabling condition, delaying diagnosis; (3) disability complicates cancer treatment decisions; and (4) problems with equipment accessibility and disability accommodations impede cancer diagnoses.

- Agaronnik N, El-Jawahri A, Iezzoni LI. Perspectives of patients with pre-existing mobility disability on the process of diagnosing their cancer. *J Gen Intern Med.* 2021;36(5):1250–1257.

In-depth interviews with 20 participants with preexisting mobility disability, subsequently diagnosed with cancer (excluding skin cancers). Concerns coalesced around five broad categories: inaccessibility of medical diagnostic equipment affecting the process of cancer diagnosis, attitudes of clinical staff about accommodating disability, dismissal of cancer signs/symptoms as emotional responses to chronic health conditions, misattributing cancer signs.

- Agaronnik ND, El-Jawahri A, Iezzoni LI. Implications of physical access barriers for breast cancer diagnosis and treatment in women with mobility disability. *J Disabil Policy Stud.* 2022;33(1):46–54.

Analyses of electronic health records of 20 patients with pre-existing chronic mobility impairment who were newly diagnosed with breast cancer between 2005 and 2017. Clinicians noted challenges positioning patients for routine procedures, including manual breast exam, screening mammography, and breast biopsies. Given challenges accommodating disability for adjuvant therapies, mastectomy was favored over breast-conserving options despite early stages of diagnosis. Notations contained little information about proactive problem solving for arranging accommodations. Notations described physical access barriers for breast cancer detection and treatment, with limited planning for mitigating barriers.

Comorbid Physical and Mental Health Conditions and Health Risk Factors, Including Obesity

AHRQ R01 HS10223. "Quality of Care and Service Use for Persons with Disabilities." PI: Lisa I. Iezzoni. 1999–2002.

- Weil E, Wachterman M, McCarthy EP, Davis RB, O'Day B, Iezzoni LI, Wee CC. Obesity among adults with disabling conditions. *JAMA.* 2002;288:1265–1268.

Analyses of the 1994–1995 National Health Interview Survey. After adjusting for sociodemographic factors, adults with a disability were more likely to be obese, with an adjusted odds ratio (AOR) of 1.9 (95% confidence interval [CI], 1.8–2.0). The highest risk occurred among adults with some (AOR, 2.4; 95% CI, 2.3–2.5) or severe (AOR, 2.5; 95% CI, 2.3–2.7) lower extremity mobility difficulties.

NIH R21 HD068756-01A1. "Pregnancy Experience of Women with Physical Disabilities." PI: Lisa I. Iezzoni. 2012–2013.

- lezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. General health, health conditions, and current pregnancy among U.S. women with and without chronic physical disabilities. *Disabil Health J.* 2014;7(2):181–188.

Analyses of responses from women ages 18–49 from the 2006–2011 National Health Interview Surveys. Among currently pregnant women with chronic physical disability (CPD), 29.1% report fair or poor health, compared with only 3.2% of nondisabled pregnant women. Currently pregnant women both with and without CPD are significantly less likely to report coexisting health conditions than nonpregnant women. Nonetheless, among currently pregnant women with CPD, only 24.5% report no coexisting conditions, while 28.7% report one, 22.8% report two, 13.2% report three, and 10.8% report four to six health conditions.

- lezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Health risk factors and mental health among U.S. women with and without chronic physical disabilities by whether women are currently pregnant. *Maternal Child Health J.* 2015;19(6):1364–1375.

Analyses of responses from women ages 18–49 from the 2006–2011 National Health Interview Surveys. Across all women regardless of chronic physical disability (CPD), women reporting current pregnancy are significantly less likely to currently smoke tobacco and report certain mental health problems. Among currently pregnant women only, women with CPD are more likely to smoke cigarettes every day (12.2%) versus 6.3% for pregnant women without CPD ($p \leq 0.001$). Among currently pregnant women, 17.7% of women with CPD have BMIs in the non-overweight range, compared with 40.1% of women without CPD ($p \leq 0.0001$). Currently pregnant women with CPD are significantly more likely to report having any mental health problems: 66.6%, compared with 29.7% among women without CPD ($p \leq 0.0001$).

NIH R01 HD091211-01A1. “Surveying Physicians to Understand Health Care Disparities Affecting Persons with Disabilities and Identify Approaches to Improve Their Care.” PI: Lisa I. lezzoni. 2018–2022.

- Agaronnik N, Lagu T, DeJong C, Perez-Caraballo A, Reimold K, Resselam J, lezzoni LI. Accommodating patients with obesity and mobility difficulties: observations from physicians. *Disabil Health J.* 2021;14(1):100951.

Analyses of three videoconference focus groups with physicians. Observations coalesced around four themes: (1) difficulty routinely tracking weight, (2) reluctance to transfer obese patients to exam tables, (3) physical barriers to diagnostic testing, and (4) weight stigma.

AHRQ R03 HS009539. “Health Care Access for Deaf Persons.” PI: Steven L. Barnett. 1997–1998.

- Barnett S, Franks P. Smoking and deaf adults: Associations with age at onset of deafness. *Am Ann Deaf.* 1999;144(1):44–50.

Analyses of National Health Interview Survey (NHIS) data from 1990–1991, years that the NHIS core questionnaire included a Hearing Supplement, including questions about age at onset of becoming deaf. For the analyses, the researchers created three groups of adults: those who became deaf before age 3 years, those who became deaf after age 3 years, and a comparison group of adults who are not deaf. Multivariate analyses revealed that adults deaf since before age 3 years were less likely to be current smokers than non-deaf adults (adjusted odds ratio

[AOR], 0.48; 95% CI, 0.23–0.99), whereas adults who became deaf after age 3 years were as likely to be current smokers as non-deaf adults (AOR, 1.07; 95% CI, 0.86–1.33). In this sample, from 1990–1991, adults deaf since before age 3 years also had less education and lower income than non-deaf adults; low education and low income are associated with higher smoking prevalence in other populations. Analyses that combined data from distinct subpopulations of deaf adults obscured differences and disparities.

- Barnett S, Franks P. Deafness and mortality: Analyses of linked data from the National Health Interview Survey and National Death Index. *Public Health Rep.* 1999;114(4):330–336.

Analyses of National Health Interview Survey (NHIS) data from 1990–1991, years that the NHIS core questionnaire included a Hearing Supplement, including questions about age at onset of becoming deaf. For the analyses, the researchers created three groups of adults: those who became deaf before age 3 years, those who became deaf after age 3 years, and a comparison group of adults who are not deaf. Multivariate analyses adjusted for sociodemographics and stratified by age found that adults who became deaf after age 3 years were more likely to die in the given time frames than non-deaf adults. However, when analyses were also adjusted for health status, there was no difference in mortality for adults who became deaf after age 3 years compared with non-deaf adults. There was no difference in mortality comparing adults who became deaf before age 3 years and non-deaf adults. Analyses that combined data from distinct subpopulations of deaf adults obscured differences and disparities.

- Barnett S, Franks P. Telephone ownership and deaf people: Implications for telephone surveys. *Am J Public Health.* 1999;89(11):1754–1756.

Analyses of National Health Interview Survey (NHIS) data from 1990–1991, years that the NHIS core questionnaire included a Hearing Supplement, including questions about age at onset of becoming deaf. For the analyses, the researchers created three groups of adults: those who became deaf before age 3 years, those who became deaf after age 3 years, and a comparison group of adults who are not deaf. Multivariate analyses revealed that adults deaf since before age 3 years were less likely to own a telephone than non-deaf adults (adjusted odds ratio [AOR], 0.35; 95% CI, 0.15–0.82), whereas adults who became deaf after age 3 years were as likely to own a telephone as non-deaf adults (AOR, 1.00; 95% CI, 0.78–1.28). In this sample, from 1990–1991, adults deaf since before age 3 years appear to be less likely to be represented in telephone-based public health surveillance.

- Barnett S, Franks P. Health care utilization and adults who are deaf: Relationship with age at onset of deafness. *Health Serv Res.* 2002;37(1):105–120.

Analyses of National Health Interview Survey (NHIS) data from 1990–1991, years that the NHIS core questionnaire included a Hearing Supplement, including questions about age at onset of becoming deaf. For the analyses, the researchers created three groups of adults: those who became deaf before age 3 years, those who became deaf after age 3 years, and a comparison group of adults who are not deaf. Multivariate analyses revealed that, compared with non-deaf adults, adults deaf since before age 3 years had fewer physician visits and were less likely to have visited a physician in the preceding 2 years, whereas adults who became deaf after age 3 years had more physician visits and were more likely to have visited a physician in the preceding

2 years. Women who became deaf after age 3 years were less likely to have had a mammogram in the previous 2 years compared with non-deaf women. Analyses that combined data from distinct subpopulations of deaf adults obscured differences and disparities.

AHRQ K08 HS15700. “Deaf People and Healthcare.” PI: Steven L. Barnett. 2006–2012.

- Barnett S, Klein JD, Pollard RQ Jr, Samar V, Schlehofer D, Starr M, Sutter E, Yang H, Pearson TA. Community participatory research with deaf sign language users to identify health inequities. *Am J Public Health*. 2011;101(12):2235–2238.

Analyses of data from the Rochester Deaf Health Survey (RDHS, 2006; U48 DP001910), a survey administered in American Sign Language (ASL) via a touchscreen kiosk, and the local Behavioral Risk Factor Surveillance System (BRFSS) administered via telephone by the Monroe County Department of Public Health. Our analyses identified deaf community strengths (e.g., a low prevalence of current smokers: 9.1% RDHS, compared with 18.1% MC BRFSS) and three glaring health inequities: obesity (34.2% RDHS vs 26.6% MC BRFSS), partner violence—ever physically abused (21.0% RDHS vs 13.9% MC BRFSS)—and suicide risk—attempted suicide in the past year (2.2% RDHS vs 0.4% MC BRFSS).

NIH T32 MH020061. “Postdoctoral Training in Suicide Prevention Research.” PI: Yeates Conwell. 2001–2021.

- Simning A, Fox ML, Barnett SL, Sorensen S, Conwell Y. Depressive and anxiety symptoms in older adults with auditory, vision, and dual sensory impairment. *J Aging Health*. 2019;31(8):1353–1375.

Analyses of data from the National Health and Aging Trends Study (NHATS; U01 AG032947) (n = 7,507). The objective of the study is to examine the association of auditory, vision, and dual sensory impairment (DSI) with late-life depressive and anxiety symptoms. Multivariable analyses accounted for sociodemographics, medical comorbidity, and functional impairment. Clinically significant depressive and anxiety symptoms were more common in those with auditory (21.1% depression and 22.0% anxiety, respectively), vision (28.4% and 23.0%), and DSI (46.2% and 36.7%) than in older adults with no auditory or vision impairment (12.6% and 10.3%). Screening older adults with sensory impairments for depression and anxiety and screening those with late-life depression and anxiety for sensory impairments may identify treatment opportunities to optimize health and well-being.

- Fox ML, James TG, Barnett S. Understanding suicidal behaviors and help-seeking attitudes among deaf and hard-of-hearing college students. *Suicide Life Threat Behav*. 2020;50(2):387–396.

Analyses of data from the American College Health Assessment-National College Health Association Form IIb (Fall 2011–Spring 2015; n = 500,860). Multinomial and binary logistic regressions determined the relation between hearing status, suicide ideation and attempt, and help-seeking. A higher proportion of deaf and hard-of-hearing (D/HH) students reported ever having seriously considered suicide (35.1% vs. 21.8%) and having ever attempted suicide (17.2% vs. 8.3%) compared with hearing students. These results should be considered in context to the limitations of the survey. D/HH persons are likely to be underrepresented in this data set,

because D/HH persons are underrepresented in college and because the ACHA-NCHA-IIb item for hearing status likely does not identify all D/HH students.

Pregnancy and Reproductive Health

NIH R21 HD068756-01A1. "Pregnancy Experience of Women with Physical Disabilities." PI: Lisa I. Iezzoni. 2012–2013.

- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Prevalence of current pregnancy among U.S. women with and without chronic physical disabilities. *Med Care*. 2013;51(6):555–562.

Analyses of responses from women ages 18–49 from the 2006–2011 National Health Interview Surveys. Compared with other women, women with chronic physical disability (CPD) are significantly older, more likely to be Black and less likely to be Asian or Hispanic, more likely to be divorced or separated, more likely to have less than a high school education, and less likely to be employed; they also have much lower incomes. Across all women, 3.5% report being currently pregnant: 3.8% of women without CPD and 2.0% with CPD. Controlling for sociodemographic factors, the adjusted odds ratio (95% confidence interval [CI]) of current pregnancy is 0.83 (95% CI, 0.65–1.05; P = 0.12) for women with CPD compared with nondisabled women.

- Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Effects of disability on pregnancy experiences among women with impaired mobility. *Acta Obstet Gynecol Scand*. 2015;94(2):133–140.

Qualitative analyses of telephone interviews with 22 women with significant mobility difficulties who had delivered babies within the prior 10 years. Impairment-related complications during pregnancy included falls; urinary tract and bladder problems; wheelchair fit and stability problems that reduced mobility and compromised safety; significant shortness of breath, sometimes requiring respiratory support; increased spasticity; bowel management difficulties; and skin integrity problems (this was rare, but multiple women greatly increased skin monitoring during pregnancy to prevent pressure ulcers).

- Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. "How did that happen?" Public responses to women with mobility disability during pregnancy. *Disabil Health J*. 2015;8(3):380–387.

Qualitative analyses of telephone interviews with 22 women with significant mobility difficulties who had delivered babies within the prior 10 years. Eighteen women described memorable interactions with strangers relating to their pregnancies or newborn babies. Strangers' statements fell into six categories: (1) curious; (2) intrusively and persistently curious; (3) hostile, including concerns that taxpayers would end up supporting the mother and child; (4) questioning woman's competence as a potential parent; (5) oblivious, not recognizing visible pregnancy or motherhood; and (6) positive. Many women reported strangers asking how their pregnancy had happened. The women doubted that visibly pregnant women without disabilities evoke the same reactions from strangers.

- Smeltzer SC, Wint AJ, Ecker JL, Iezzoni LI. Labor, delivery, and anesthesia experiences of women with physical disability. *Birth*. 2017;44(4):315–324.

Qualitative analyses of telephone interviews with 22 women with significant mobility difficulties who had delivered babies within the prior 10 years. Four key themes emerged from participants'

narratives of laboring and giving birth with a disability: women's preferences for type of delivery, clinicians and some women expected no labor pain, fears prompting active advocacy, and positive experiences. As participants discussed their experiences with anesthesia, four additional themes were identified: importance of consultation with the anesthesia team, decisions about epidural/spinal vs. general anesthesia, failed epidural with repeated efforts, and fear of injury related to anesthesia. The responses of women in this study suggest that there is a need to make intrapartum care better for women with physical disabilities and to improve their experiences with labor, birth, and obstetric anesthesia care.

NIH R01 HD091211-01A1. "Surveying Physicians to Understand Health Care Disparities Affecting Persons with Disabilities and Identify Approaches to Improve Their Care." PI: Lisa I. Iezzoni. 2018–2022.

- Agaronnik N, Pendo E, Lagu T, DeJong C, Perez-Caraballo A, Iezzoni LI. Ensuring the reproductive rights of women with intellectual disability. *J Intellect Develop Disabil*. 2020;45:365–376.

Analyses of open-ended individual interviews with 20 practicing physicians and three video-based focus group interviews with an additional 22 practicing physicians. Analyses identified ableist attitudes that might compromise reproductive care for women with intellectual disability, suggesting that gaps remain in ensuring reproductive rights of women with intellectual disability.

NIH R01 HD092326. "Pregnancy in Women with Disabilities: Using Novel Methods to Characterize Risk." PIs: Hilary Brown & Yona Lunsky. 2017–2021.

- Brown HK, Chen S, Guttmann A, Havercamp SM, Parish SL, Ray JG, Vigod SN, Tarasoff LA, Lunsky Y. Neonatal outcomes of mothers with a disability. *Pediatrics*. 2022;150(3):e2021055318.

Population-based cohort study of all hospital singleton live births in Ontario, Canada, 2003–2018. Compared to newborns of women without disabilities, newborns of women with intellectual/developmental disability or with multiple disabilities had moderately higher risk of adverse outcomes, including preterm birth, neonatal morbidity, neonatal abstinence syndrome (NAS), and neonatal intensive care unit (NICU) admission. No differences in newborn outcomes were found for women with physical or sensory disabilities compared to women with no disability.

- Saeed G, Brown HK, Lunsky Y, Welsh K, Proulx L, Havercamp S, Tarasoff LA. Barriers to and facilitators of effective communication in perinatal care: a qualitative study of the experiences of birthing people with sensory, intellectual, and/or developmental disabilities. *BMC Pregnancy Childbirth*. 2022;22(1), 1–13.

Semi-structured interviews with 17 people with intellectual/developmental disabilities (e.g., autism spectrum disorder, cognitive delay) and/or sensory disabilities (e.g. d/Deaf, blind) in Ontario, Canada, who had recently given birth. Participants reported multiple barriers to effective communication in perinatal care, including lack of policies and guidelines, lack of provider experience, lack of provider effort, ableism, and provider assumptions. Facilitators included knowledgeable and supportive providers and access to communication aids and services.

- Brown HK, Chen S, Vigod SN, Guttmann A, Havercamp SM, Parish S, Tarasoff LA, Lunskey Y. A population-based analysis of postpartum acute care use among women with disabilities. *Am J Obstet Gynecol MFM*. 2022;4(3):1–11.

Population-based study in Ontario, Canada, women with a singleton obstetrical delivery from 2003 to 2019 were classified into those with physical (n = 155,500), sensory (n = 49,338), intellectual/developmental (n = 2,650), and multiple disabilities (≥ 2 disabilities; n = 9,904), and women without disabilities (n = 1,701,574). Any postpartum emergency department visit occurred in 23.5% of women without a disability, with risks elevated in women with physical (32.9%; adjusted risk ratio [ARR], 1.27), sensory (30.0%; ARR, 1.16), intellectual/developmental (48.8%; ARR, 1.38;), and multiple disabilities (42.0%; ARR, 1.44) compared with women without disabilities. Similarly, any postpartum hospital admission occurred in 3.0% of women without a disability, with elevated risks in women with physical (4.8%; ARR, 1.37), sensory (4.0%; ARR, 1.19), intellectual/developmental (9.6%; ARR, 1.96), and multiple disabilities (7.3%; ARR, 1.77).

- Khan M, Brown HK, Lunskey Y, Welsh K, Havercamp SM, Proulx L, Tarasoff LA. (2021). A socio-ecological approach to understanding the perinatal care experiences of people with intellectual and/or developmental disabilities in Ontario, Canada. *Womens Health Issues*. 2021;31(6):550–559.

Semi-structured interviews were conducted with 10 individuals with intellectual/developmental disabilities in Ontario, Canada, who had given birth within the past 5 years. Barriers at the societal (e.g., cultural norms of motherhood), policy/institutional (e.g., child protection policies and practices), interpersonal (e.g., inadequate formal and informal support), and intrapersonal levels (e.g., internalized stigma) contributed to negative perinatal care experiences. Conversely, facilitators on the interpersonal level (e.g., positive interactions with perinatal care providers and familial and social service supports) were identified as positively shaping participants' perinatal care experiences.

- Tarasoff, L, Lunskey Y, Chen S, Guttmann A, Havercamp S, Parish S, Vigod S, Carty A, Brown HK. Preconception health characteristics of women with disabilities in Ontario: A population-based, cross-sectional study. *J Womens Health (Larchmt)*. 2020;29(12):1564–1575.

Population-based cross-sectional study of 15- to 44-year-old women with physical (n = 253,184), sensory (n = 93,170), intellectual/developmental (n = 8,986), and multiple disabilities (n = 29,868) and women without these disabilities (n = 2,307,822), using Ontario health administrative data (2017–2018). Women with intellectual/developmental disabilities had the lowest income quintiles and the highest material deprivation. Compared with women without disabilities, women with physical, sensory, intellectual/developmental, and multiple disabilities had higher rates of diabetes, asthma, and stable and unstable chronic medical conditions. Higher rates of mood/anxiety disorders, psychotic disorders, self-harm, other mental illnesses, and assault were higher in disability groups compared to women without a disability.

- Brown HK, Chen S, Guttmann A, Havercamp SM, Parish S, Ray JG, Tarasoff LA, Vigod SN, Carty A, Lunskey Y. Rates of recognized pregnancy in women with disabilities in Ontario, Canada. *Am Obstet Gynecol*. 2020;222(2):189–192.

Population-based, repeated, cross-sectional study completed in Ontario, Canada. Health administrative data sets covering the whole population were linked using a unique encoded identifier. Included were women aged 15–44 years who had an identified physical, sensory, or intellectual/developmental disability, based on ≥2 physician visits or ≥1 emergency department visits or hospitalizations between database inception and study entry. Compared with women without disabilities, overall recognized pregnancy rates were slightly lower in those with physical or sensory disabilities and much lower in women with intellectual/developmental or multiple disabilities. Adolescent pregnancy rates were highest in women with intellectual/developmental disabilities and also higher in women with physical and sensory disabilities, each compared with women without disabilities.

NIH R01 HD074581. “Health Needs and Barriers to Perinatal Care for Women with Mobility Disabilities.” PI: Monika Mitra. 2013–2018.

- Nthenge S, Smith L, Ho S, Mitra M. Experiences of women of short stature during the perinatal period. *J Obstet Gynecol Neonatal Nurs*. 2022;51(4):418–427.

A qualitative study to explore the experiences of women of short stature, including women with dwarfism and osteogenesis imperfecta (OI), during the perinatal period. Four themes represented the participants’ experiences during maternity care: clinicians’ lack of knowledge, sources of information and emotional support, clinical considerations: effects of pregnancy and disability, and accessibility barriers and adaptations. Participants experienced respiratory difficulties and preterm birth. They expressed concerns regarding the lack of clinician knowledge and experience in administering epidural anesthesia to women of short stature and highlighted the important role of disability organizations in disseminating information about childbirth for women with disabilities.

- Clements KM, Zhang J, Long-Bellil LM, Mitra M. Emergency department utilization during the first year of life among infants born to women at risk of disability. *Disabil Health J*. 2020;13(1):100831.

Population-based cohort study using Massachusetts 2007–2009 birth certificates linked to 2007–2010 hospital discharge data. Of 218,599 women, 6.7% were at risk of disability. Infants born to women at risk had a higher rate of emergency department (ED) visits in their first year than infants born to women not at risk: 0.85 visits/person-year (95% confidence interval [CI], 0.84–0.87) vs. 0.55 (0.55–0.55) for term, 0.74 (0.70–0.77) vs. 0.55 (0.54–0.56) for preterm. Utilization varied by maternal diagnosis. Emergent/intermediate and nonemergent visits were both elevated among infants born to women at risk for disability. In adjusted analyses, term infants of women with musculoskeletal diagnoses (hazard ratio [HR] = 1.3, 95% CI, 1.2–1.4) and preterm infants of women with circulatory diagnoses (HR = 1.2, 95% CI, 1.0–1.3) had the highest hazards of ED visit vs. infants of women not at risk of disability.

- Smeltzer SC, Mitra M, Long-Bellil L, Iezzoni LI, Smith LD. Obstetric clinicians’ experiences and educational preparation for caring for pregnant women with physical disabilities: A qualitative study. *Disabil Health J*. 2018;11(1):8–13.

A qualitative study of semi-structured telephone interviews with 13 obstetricians and one nurse midwife. Themes identified from transcript analyses included lack of education at any level, including during postgraduate residency and fellowship on care of pregnant women with physical disability; unplanned career pathway; educating other clinicians; and positive and negative experiences providing obstetrical care to women with physical disability. Several clinicians provided this care because of requests from other clinicians and did not begin their careers with the goal of providing obstetric care to women with physical disabilities. None had received formal education or training, including during their residencies or fellowships. The clinicians described very rewarding experiences caring for women with physical disability.

- Clements KM, Mitra M, Zhang J. Antenatal hospital utilization among women at risk for disability. *J Womens Health (Larchmt)*. 2018;27(8):1026–1034.

Analysis of Massachusetts Pregnancy to Early Life Longitudinal data system linked 2007–2009 birth certificates to 2006–2009 discharges. Of 221,867 women, 4.0% were at medium/high risk of disability. Mental illness (26.9%) and circulatory system (25.2%) diagnoses were most common. More than 2% had comorbid mental/physical conditions. Women at risk for disability were more likely than women not at risk to have an antenatal emergency department (ED) (37.1% vs. 25.0%), observational stay (OS) (19.1% vs. 13.1%), or nondelivery inpatient (IP) visit (11.5% vs. 4.0%) ($p \leq 0.001$ for each). Utilization varied by diagnosis. In adjusted analyses, women with two or more physical conditions had highest rate of ED visit (hazard ratio [HR] = 2.3; 95% confidence interval [CI], 1.8–2.8) and OS/IP visit (HR = 2.9; 95% CI, 2.3–3.6) compared with women not at risk. Inadequate prenatal care was associated with increased utilization across all disability risk groups. ED visits for mental illness were high across groups.

- Mitra M, Akobirshoev I, Moring NS, Long-Bellil L, Smeltzer SC, Smith LD, Iezzoni LI. Access to and satisfaction with prenatal care among pregnant women with physical disabilities: Findings from a national survey. *J Womens Health (Larchmt)*. 2017;26(12):1356–1363.

Survey of maternity care access and experiences of women with physical disabilities from 37 states. A total of 126 women with various physical disability types from 37 states completed the survey. Almost half of the respondents (53.2%) reported that their physical disability was a big factor in their selection of a maternity care provider, and 40.3% of women reported that their prenatal care provider knew little or nothing about the impact of their physical disability on their pregnancy. Controlling for maternal demographic characteristics and use of mobility equipment, women who reported that their prenatal care provider lacked knowledge of disability and those who felt they were not given adequate information were more likely to report unmet needs for prenatal care.

- Long-Bellil L, Mitra M, Iezzoni LI, Smeltzer SC, Smith LD. Experiences and unmet needs of women with physical disabilities for pain relief during labor and delivery. *Disabil Health J*. 2017;10(3):440–444.

Semi-structured interviews with 25 women with physical disabilities from across the United States. Women expressed specific preferences for the method of pain relief. Some confronted systemic barriers in exploring their options for pain relief, while others were given a choice. At times, anesthesiologists lacked knowledge and experience in caring for women with disabilities.

Conversely, some women described how the administration of anesthesia was meticulously planned and attributed their positive labor and delivery experiences to this careful planning.

- Mitra M, Smith LD, Smeltzer SC, Long-Bellil LM, Sammet Moring N, Iezzoni LI. Barriers to providing maternity care to women with physical disabilities: Perspectives from health care practitioners. *Disabil Health J.* 2017;10(3):445–450.

Semi-structured telephone interviews with 14 health care practitioners in the United States who provide maternity care to women with physical disabilities, as identified by affiliation with disability-related organizations, publications, and snowball sampling. Participant-reported barriers to providing optimal maternity care to women with physical disabilities were grouped into four levels: practitioner level (e.g., unwillingness to provide care), clinical practice level (e.g., accessible office equipment, such as adjustable exam tables), system level (e.g., time limits, reimbursement policies), and barriers relating to lack of scientific evidence (e.g., lack of disability-specific clinical data).

- Clements KM, Mitra M, Zhang J, Iezzoni LI. Pregnancy characteristics and outcomes among women at risk for disability from health conditions identified in medical claims. *Womens Health Issues.* 2016;26(5):504–510.

Analysis of 2006 through 2009 Massachusetts Pregnancy to Early Life Longitudinal data system linked birth certificate and hospital claims one year pre-pregnancy through delivery. Of 221,867 women, 14,701 (6.6%) were at medium or high risk of disability. Health conditions were classified as circulatory (23%), musculoskeletal (10%), nervous system/sensory (13%), other physical (19%), two or more physical (5%), mental illness (24%), and comorbid mental/physical (6%). Women at risk of disability were more likely than others to have socioeconomic and pregnancy risks and adverse infant and maternal outcomes. Socioeconomic and risk profile varied by health condition category. Adjusted risk ratios for preterm birth ranged from 1.2 (95% confidence interval [CI], 1.1–1.4) for women with nervous system/sensory diagnoses to 1.6 (95% CI, 1.4–1.9) for women with two or more physical diagnoses; risk ratios for maternal delivery hospitalization for more than 5 days ranged from 1.5 (95% CI, 1.2–1.9) for women with musculoskeletal diagnoses to 3.0 (95% CI, 2.5–3.6) for women with comorbid mental/physical diagnoses.

- Mitra M, Long-Bellil LM, Iezzoni LI, Smeltzer SC, Smith LD. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disabil Health J.* 2016;9(3):457–463.

Twenty-five phone interviews with women with physical disabilities from across the United States who had a baby in the past 10 years. Women reported a wide range of disabling conditions. Analysis revealed three broad themes related to unmet needs during pregnancy among women with physical disabilities: (1) clinician knowledge and attitudes, (2) physical accessibility of health care facilities and equipment, and (3) need for information related to pregnancy and postpartum supports. The women also provided recommendations to other women with disabilities who are currently pregnant or thinking of becoming pregnant. Recommendations related to finding a clinician one trusts, seeking peer support, self-advocating, and preparing oneself for the baby.

- Mitra M, Clements KM, Zhang J, Smith LD. Disparities in adverse preconception risk factors between women with and without disabilities. *Matern Child Health J.* 2015;20(3):507–515.

Analysis of 2010 Behavioral Risk Factor Surveillance System data to estimate the prevalence of health behaviors, health status indicators, and preventive health care among non-pregnant women ages 18–44 years with (N = 8,370) and without (N = 48,036) disabilities. Women with disabilities were more likely than women without disabilities to currently smoke (30.5% vs. 14.5%, $p < 0.0001$) and less likely to exercise in the past month (67.1% vs. 79.8%, $p < 0.0001$). Heavy drinking was similar in the two groups (4.4% vs. 4.5%, $p = 0.9$). Health status indicators were worse among women with disabilities, with 35.0% reporting fair/poor health and 12.4% reporting diabetes, compared with 6.7% and 5.6%, respectively, among women with no disabilities ($p < 0.0001$ for both). Frequent mental distress, obesity, asthma, and lack of emotional support were also higher among women with disabilities compared with their non-disabled counterparts. Women with disabilities were more likely to receive some types of preventive care (e.g., HIV tests), but less likely to receive others (e.g., recent dental cleaning, routine checkups). Disparities in health behaviors and health status indicators between the two groups remained after adjusting for socio-demographic factors.

- Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal characteristics, pregnancy complications, and adverse birth outcomes among women with disabilities. *Med Care.* 2015;53(12):1027–1032.

Analysis of data from the 2002–2011 Rhode Island Pregnancy Risk Assessment Monitoring System (PRAMS) survey. Approximately 7% of women in Rhode Island reported a disability. Women with disabilities reported significant disparities in their health care utilization, health behaviors and health status before and during pregnancy and during the postpartum period. Compared to nondisabled women, they were significantly more likely to report stressful life events and medical complications during their most recent pregnancy, less likely to receive prenatal care in the first trimester, and more likely to have preterm births (13.4%; 95% confidence interval [CI], 11.6–15.6, compared to 8.9%; 95% CI, 8.5–9.3 for women without disabilities) and low birth weight babies (10.3%; 95% CI, 9.4–11.2, compared to 6.8%; 95% CI, 6.8–6.9). There was no difference in the rates of cesarean section between women with and without disabilities.

- Mitra M, Iezzoni LI, Zhang J, Long-Bellil LM, Smeltzer SC, Barton BA. Prevalence and risk factors for postpartum depression symptoms among women with disabilities. *Matern Child Health J.* 2014;19(2):362–372.

Analysis of data from the 2009–2011 Rhode Island Pregnancy Risk Assessment Monitoring System (PRAMS). Almost 30% (28.9%; 95% confidence interval [CI], 22.8–35.8) of mothers with disabilities reported often or always feeling down, depressed, or sad after childbirth compared to 10% of those without disabilities (95% CI, 8.9–11.3). Compared to other women in the study, women with disabilities had a greater likelihood for postpartum depression (PPD) symptoms (RR 1.6; 95% CI, 1.1–2.2) after accounting for sociodemographics, maternal characteristics related to PPD, and depression before and during pregnancy. Adjusting for other covariates, self-reported prenatal diagnosis of depression was not associated with symptoms of PPD, and depression

during pregnancy was marginally associated with PPD symptomatology for women with disabilities. Women with disabilities are at a greater risk of experiencing symptoms of postpartum depression than other women.

Partially funded by: NIH R01 HD074581. "Health Needs and Barriers to Perinatal Care for Women with Mobility Disabilities." PI: Monika Mitra. 2013–2018; NIH R01 HD082105. "Improving Pregnancy Outcomes of Women with Intellectual and Developmental Disabilities." PIs: Monika Mitra & Susan L. Parish. 2015–2021; and NIH R01 HD090103. "Pregnancy Outcomes and Experiences among Deaf and Hard of Hearing Women." PIs: Monika Mitra & Michael M. McKee. 2017–2023.

- Horner-Johnson W, Akobirshoev I, Amutah-Onukagha NN, Slaughter-Acey JC, Mitra M. Preconception health risks among U.S. women: disparities at the intersection of disability and race or ethnicity. *Womens Health Issues*. 2021;31(1):65–74.

Analysis of 2016 Behavioral Risk Factor Surveillance System to estimate the prevalence of preconception health risks among nonpregnant women 18–44 years of age. A modified Poisson regression was used to compare non-Hispanic white women with disabilities and women with and without disabilities in three other race/ethnicity groups (non-Hispanic Black, Hispanic, other race) to a reference group of non-Hispanic white women without disabilities. In every racial and ethnic group, women with disabilities had a significantly higher prevalence of most preconception health risks than their counterparts without disabilities. The disparity in obesity for Black women with disabilities was additive, with the adjusted prevalence ratio (PR, 1.77; 95% confidence interval [CI], 1.57–2.00) equal to the sum of the effects for disability alone (PR, 1.29; 95% CI, 1.19–1.41) and Black race alone (PR, 1.47; 95% CI, 1.36–1.58).

NIH R01 HD082105. "Improving Pregnancy Outcomes of Women with Intellectual and Developmental Disabilities." PIs: Monika Mitra & Susan L. Parish. 2016–2021.

- Smith LD, Valentine A, Moore Simas TA, Parish SL, Levy A, Mitra M. Clinician-reported barriers to providing perinatal care to women with intellectual and developmental disabilities. *J Intellect Dev Disabil*. Published online June 30, 2022.

Semi-structured interviews and one focus group with U.S. obstetric care clinicians (n = 17). The majority of participants were white, non-Hispanic, and female. Participants reported barriers providing care to pregnant women with intellectual and developmental disabilities across individual (e.g., communication challenges), practice (e.g., identification of disability status), and system levels (e.g., lack of clinician training).

- Amir N, Smith LD, Valentine AM, Mitra M, Parish SL, Moore Simas TA. Clinician perspectives on the need for training on caring for pregnant women with intellectual and developmental disabilities. *Disabil Health J*. 2022;15(2):101262.

Qualitative individual interviews (n = 9) and one focus group (n = 8) with obstetric clinicians who self-reported experience caring for women with intellectual and developmental disabilities (IDDs) during pregnancy. Analysis revealed three main themes. First, there is a need for obstetric training and education: No participant reported receiving any training in caring for pregnant women with IDD. Participants expressed a need for formal education. Second, there were recommendations for formal training: Participants noted the need for training during residency

and beyond, and all healthcare staff members should be included in training. Third, training outcomes should increase knowledge, enhance attitudes, and develop practical skills related to care for pregnant women with IDD.

- Mitra M, Akobirshoev I, Valentine A, Brown HK, Moore Simas TA. Severe maternal morbidity and maternal mortality in women with intellectual and developmental disabilities. *Am J Prev Med.* 2021;61(6):872–881.

Analysis of 2004–2017 Healthcare Cost and Utilization Project Nationwide Inpatient Sample data. This study identified 32,324 deliveries to women with intellectual and developmental disabilities. Per 10,000 deliveries, 566 deliveries with severe maternal morbidity occurred in women with intellectual and developmental disabilities, compared with 239 in women without intellectual and developmental disabilities. Women with intellectual and developmental disabilities had greater risk of both severe maternal morbidity (risk ratio = 2.36; 95% confidence interval [CI], 2.06–2.69) and nontransfusion severe maternal morbidity (risk ratio = 2.95; 95% CI, 2.42–3.61) in unadjusted analyses, which was mitigated in adjusted analyses for sociodemographic characteristics (risk ratio = 1.74; 95% CI, 1.47–2.06; risk ratio = 1.85, 95% CI, 1.42–2.41) and the expanded obstetric comorbidity index (risk ratio = 1.23, 95% CI, 1.04–1.44; risk ratio = 1.31; 95% CI, 1.02–1.68). The unadjusted incidence of maternal mortality in women with intellectual and developmental disabilities was 284 per 100,000 deliveries, nearly fourfold higher than in women without intellectual and developmental disabilities (69 per 100,000 deliveries; risk ratio = 4.07; 95% CI, 2.04–8.12), and the risk remained almost threefold higher after adjustment for sociodemographic characteristics (risk ratio = 2.86; 95% CI, 1.30–6.29) and the expanded obstetric comorbidity index (risk ratio = 2.30; 95% CI, 1.05–5.29).

- Amir N, Mitra M, Leung K, Moore Simas TA. Complications following hysterectomy in women with intellectual and developmental disabilities. *Disabil Health J.* 2022;15(1):101213.

Analysis of data from the National Inpatient Sample from 2014 to 2017. Of eligible women undergoing hysterectomy, 1,370 were identified as having intellectual and developmental disabilities (IDD) and 624,700 did not. Compared to controls, women with IDD were significantly younger (45 vs. 50 years, $p < 0.001$). Women with IDD were also more likely to have had governmental health insurance (83% vs. 34%, $p < 0.001$), an open hysterectomy approach (78% vs. 69%, $p = 0.002$), and longer hospital stays (4 days vs. 3 days, $p < 0.001$). After adjusting for potential confounders, women with IDD had greater odds of postoperative urinary complications (odds ratio [OR] = 3.74; 95% CI, 1.18–11.83) and complications related to decubitus ulcer formation (OR 8.97; 95% CI, 2.10–38.36).

- Akobirshoev I, Mitra M, Parish SL, Valentine A, Simas TAM. Racial and ethnic disparities in birth outcomes and labor and delivery charges among Massachusetts women with intellectual and developmental disabilities. *Intellect Dev Disabil.* 2020;58(2):126–138.

Analysis of data from the 1998–2013 Massachusetts Pregnancy to Early Life Longitudinal (PELL) data system. There was significant preterm birth disparity among non-Hispanic Black women with intellectual and developmental disabilities (IDD) compared to their non-Hispanic white peers. There were also significant racial and ethnic differences in associated labor and delivery-related charges.

- Mitra M, Akobirshoev I, Parish SL, Valentine A, Clements KM, Moore Simas TA. Postpartum emergency department use among women with intellectual and developmental disabilities: a retrospective cohort study. *J Epidemiol Community Health*. 2019;73(6):557–563.

Analysis of 2002–2010 Massachusetts Pregnancy to Early Life Longitudinal data. We identified 776 births in women with intellectual and developmental disabilities (IDD) and 595,688 births in women without IDD. Across all three postpartum periods, women with IDD were vastly more likely to have any postpartum emergency department (ED) use, ≥ 2 ED visits, and ED visits for mental health reasons. These findings persisted after controlling for numerous sociodemographic and clinical characteristics. Women with IDD were less likely to have non-urgent ED visits during the three postpartum periods and were less likely to have primary-care sensitive ED visits during the postpartum period.

- Akobirshoev I, Mitra M, Parish SL, Moore Simas TA, Dembo R, Ncube CN. Racial and ethnic disparities in birth outcomes and labour and delivery-related charges among women with intellectual and developmental disabilities. *J Intellect Disabil Res*. 2018;63(4):313–326.

Secondary analysis of the 2004–2011 Healthcare Cost and Utilization Project National Inpatient Sample. There were 2,110 delivery-associated hospitalizations identified among women with intellectual and developmental disabilities (IDD), including 1,275 among non-Hispanic white women, 527 among non-Hispanic Black women, and 308 among Hispanic women. We found significant disparities in stillbirth among non-Hispanic Black and Hispanic women with IDD compared with their non-Hispanic white peers (odds ratio [OR] = 2.50, 95% confidence interval [CI], 1.16–5.28, $P < 0.01$; and OR = 2.53, 95% CI, 1.08–5.92, $P < 0.01$, respectively). There were no racial and ethnic disparities in caesarean delivery, preterm birth, and small-for-gestational-age neonates among women with IDD. The average labor and delivery-related charges for non-Hispanic Black and Hispanic women with IDD (\$18,889 and \$22,481, respectively) exceeded those for non-Hispanic white women with IDD (\$14,886) by \$4,003 and \$7,595 or by 27% and 51%, respectively. The significant racial and ethnic differences in charges persisted even after controlling for a range of individual-level and institutional-level characteristics and were 6% ($\ln(\beta) = 0.06$; 95% CI, 0.01–0.11, $P < 0.05$) and 9% ($\ln(\beta) = 0.09$; 95% CI, 0.03–0.14, $P < 0.01$) higher for non-Hispanic Black and Hispanic women with IDD compared with non-Hispanic white women with IDD.

- Li H, Mitra M, Wu JP, Parish SL, Valentine A, Dembo RS. Female sterilization and cognitive disability in the United States, 2011–2015. *Obstet Gynecol*. 2018;132(3):559–564.

Secondary analysis of nationally representative data from the National Survey of Family Growth 2011–15, which surveyed women aged 15–44 in the U.S. civilian population. Female sterilization rates were higher among women with cognitive (22.1%, $n = 272$) and non-cognitive disabilities (24.7%, $n = 150$) than among women without disabilities (14.8%, $n = 1,132$). After adjusting for sociodemographic covariates, women with cognitive disabilities had significantly higher odds of female sterilization (adjusted odds ratio [aOR] = 1.54; 95% confidence interval [CI] 1.19–1.98, $p < .01$), and hysterectomy (aOR = 2.64; 95% CI, 1.53–4.56, $p < .001$) than women without cognitive disabilities. Women with cognitive disabilities also underwent sterilization at significantly younger ages (27.3 years; 95% CI, 27.0–27.6) than women with non-cognitive

disabilities (28.3 years; 95% CI, 27.9–28.8) and women without any disability (29.8 years; 95% CI, 29.5–30.0).

- Wu J, Zhang J, Mitra M, Parish SL, Minama Reddy GK. Provision of moderately and highly effective reversible contraception to insured women with intellectual and developmental disabilities. *Obstet Gynecol.* 2018;132(3):565–574.

Analysis of data from the Massachusetts All-Payer Claims Database. Among 915,561 women who were not medically or surgically sterile, 13,059 women (1.4%) had at least one intellectual and developmental disability. Women with intellectual and developmental disabilities were less likely to be provided long-acting reversible contraception (LARC) (2.1% vs. 4.2%, $p < 0.001$, adjusted odds ratio [aOR] 0.43, 95% CI 0.38–0.48, $p < 0.001$) and moderately effective methods (21.1% vs. 29.9%, $p < 0.001$, aOR 0.68, 95% CI 0.65–0.71, $p < 0.001$) than women without intellectual and developmental disabilities. The one exception was the progestin shot, which was provided more often to women with intellectual and developmental disabilities than to women without these disabilities (14.7% vs. 4.3%, $p < 0.001$). Among a subset of women who only received moderately effective methods or LARC ($n = 310,344$), women with intellectual and developmental disability had lower odds of receiving LARC than moderately effective methods (aOR 0.59, 95% CI 0.52–0.67).

- Mitra M, Parish SL, Akobirshoev I, Rosenthal E, Moore Simas TA. Postpartum hospital utilization among Massachusetts women with intellectual and developmental disabilities: A retrospective cohort study. *Matern Child Health J.* 2018;22(10):1492–1501.

Analysis of data from the 2002–2012 Pregnancy to Early Life Longitudinal Data System. Women with IDD had markedly higher rates of postpartum hospital admissions and emergency department (ED) visits during the critical postpartum periods (within 1–42, 43–90, and 91–365 days) after a childbirth.

- Mitra M, Parish SL, Clements KM, Zhang J, Simas TAM. Antenatal hospitalization among U.S. women with intellectual and developmental disabilities: A retrospective cohort study. *Am J Intellect Dev Disabil.* 2018;123(5):399–411.

Retrospective cohort study examining the prevalence of hospital utilization during pregnancy and the primary reason for antenatal hospital utilization among women with intellectual and developmental disabilities (IDD). Women with IDD were more likely to have an antenatal emergency department (ED) visit, observational stays, and non-delivery hospital stays. This study highlights the need for further understanding of the health care needs of women with IDD during pregnancy.

- Akobirshoev I, Parish SL, Mitra M, Rosenthal E. Birth outcomes among US women with intellectual and developmental disabilities. *Disabil Health J.* 2017;10(3):406–412.

Analysis of data from the 2007–2011 Nationwide Inpatient Sample of the Healthcare Cost and Utilization Project (HCUP) to compare birth outcomes in women with and without intellectual and developmental disabilities (IDD). Of an estimated 20.6 million deliveries identified through the HCUP 2007–2011 data, 10,275 occurred in women with IDD. In adjusted regression analyses, women with IDD were significantly more likely to have preterm birth (odds ratio [OR] = 1.46; 95%

confidence interval [CI], 1.26–1.69, $p < 0.001$), low birth weight (OR = 1.61; 95% CI, 1.27–2.05, $p < 0.001$), and stillbirth (OR = 2.40; 95% CI, 1.70–3.40, $p < 0.001$) compared to those without IDD.

NIH R01 HD090103. “Pregnancy Outcomes and Experiences among Deaf and Hard of Hearing Women.”
PIs: Monika Mitra & Michael M. McKee. 2017–2023.

- James TG, Helm, KVT, Ratakonda S, Smith L, Mitra M. Health literacy and difficulty accessing information about the COVID-19 pandemic among deaf and hard-of-hearing people. *HLRP: Health Literacy: Research and Practice*. In press.

Analysis of data from a web-based survey of deaf and hard-of-hearing (DHH) people who gave birth in the last 10 years. Of the total sample (n = 421), approximately 17% had limited health literacy, and 22% reported experiencing difficulty accessing information about COVID-19. In adjusted analyses, respondents with limited health literacy (adjusted odds ratio [aOR] = 2.245) and Hispanic ethnicity (aOR = 2.149) had higher risk of reporting information access barriers. There was no association between language preference and reporting COVID-19 information barriers. However, DHH individuals with limited health literacy were at higher risk of experiencing information marginalization during the ongoing COVID-19 pandemic, highlighting the need for tailored information based on access needs.

- McKee MM, Zhang J, Akobirshoev I, McKee K, Mitra M. Antenatal emergency department and inpatient use among Massachusetts deaf and hard of hearing women: A retrospective cohort study. *Research Square*. Published online December 6, 2021.

Retrospective cohort study design to analyze 2002–2013 Massachusetts Pregnancy to Early Life Longitudinal data to compare antenatal inpatient and emergency department use between deaf and hard of hearing (DHH) (N = 925) and hearing (N = 2,895) women with singleton deliveries. Among DHH women, 49% had at least one emergency department visit, 19% had an observational stay, and 14% had a non-delivery hospital stay, compared to 26%, 14%, and 6%, respectively among hearing women during the antenatal period (all $p < 0.001$). The risk of non-delivery emergency department visits (relative risk [RR] = 1.58; $p < 0.001$) and inpatient stays (RR 1.89; $p < 0.001$) remained higher among DHH women compared to hearing women even after adjustment for relevant variables. Having four or more emergency department visits (7% vs. 2%), two or more observational stays (7% vs. 3%) and two or more non-delivery hospital stays (4% vs. 0.4%) prior to delivery were more common among pregnant DHH women compared to controls (all $P < 0.001$).

- Wu JP, Zhang J, McKee M, Akobirshoev I, McKee KS, Mitra M. Contraceptive provision and quality care measures for insured individuals in Massachusetts who are deaf or hard of hearing. *Obstet Gynecol*. 2021;138(3):398–408.

Claims analysis of data from the 2014 Massachusetts All-Payer Claims Database. Among the 1,171,838 enrollees at risk for pregnancy, 13,400 (1.1%) were deaf or hard of hearing (DHH). Among DHH individuals, 31.4% were provided contraception (23.5% prescription contraception, 5.4% long-acting reversible contraception [LARC], 0.7% tubal sterilization). DHH individuals were less likely to receive prescription contraception (adjusted odds ratio 0.92; 95% confidence

interval [CI], 0.88–0.96) than individuals who were not DHH. The percentage of individuals who were DHH who received most effective or moderately effective methods was less than that for individuals who were not (24.2% vs 26.3%, $P < .001$). There were no differences in provision of LARC or permanent contraception by DHH status.

- Mitra M, McKee MM, Akobirshoev I, Ritter GA, Valentine AM. Pregnancy and neonatal outcomes among deaf and hard of hearing women: Results from nationally representative data. *Womens Health Issues*. 2021;31(5):470–477.

Analysis of data from the 2007–2016 Healthcare Cost and Utilization Project National Inpatient Sample to compare pregnancy complications and outcomes among deliveries to deaf or hard of hearing (DHH) women with deliveries to non-DHH women. DHH women had an increased risk of adverse pregnancy outcomes and chronic medical conditions, including preexisting diabetes (relative risk [RR], 2.01; 95% confidence interval [CI], 1.68–2.42; $p < .001$), gestational diabetes (RR, 1.31; 95% CI, 1.19–1.44; $p < .001$), chronic hypertension (RR, 1.51; 95% CI, 1.33–1.72; $p < .001$), preeclampsia and eclampsia (RR, 1.35; 95% CI, 1.21–1.51; $p < .01$), placenta previa (RR, 1.62; 95% CI, 1.22–2.16; $p < .01$), placental abruption (RR, 1.43; 95% confidence interval, 1.15–1.78; $p < .01$), labor induction (RR, 1.16; 95% CI, 1.05–1.27; $p < .01$), chorioamnionitis (RR, 1.43; 95% CI, 1.22–1.69; $p < .001$), cesarean delivery (RR, 1.09; 95% CI, 1.04–1.14; $p < .001$), premature rupture of membranes (RR, 1.34; 95% CI, 1.20–1.50; $p < .001$), antepartum hemorrhage (RR, 1.36; 95% CI, 1.13–1.64; $p < .001$), and postpartum hemorrhage (RR, 1.30; 95% CI, 1.13–1.49; $p < .001$). After adjustment for socioeconomic and hospital characteristics, the risk for gestational diabetes, preeclampsia and eclampsia, placenta previa, and chorioamnionitis remained unexplained.

- Mitra M, McKee MM, Akobirshoev I, Valentine A, Ritter G, Zhang J, McKee K, Iezzoni LI. Pregnancy, birth, and infant outcomes among women who are deaf or hard of hearing. *Am J Prev Med*. 2020;58(3):418–426.

Analysis of data from the 2007–2016 Healthcare Cost and Utilization Project National Inpatient Sample to compare pregnancy complications and outcomes among deliveries to deaf or hard of hearing (DHH) women with deliveries to non-DHH women. DHH women had an increased risk of adverse pregnancy outcomes and chronic medical conditions, including preexisting diabetes (relative risk [RR], 2.01; 95% confidence interval [CI], 1.68–2.42; $p < .001$), gestational diabetes (RR, 1.31; 95% CI, 1.19–1.44; $p < .001$), chronic hypertension (RR, 1.51; 95% CI, 1.33–1.72; $p < .001$), preeclampsia and eclampsia (RR, 1.35; 95% CI, 1.21–1.51; $p < .01$), placenta previa (RR, 1.62; 95% CI, 1.22–2.16; $p < .01$), placental abruption (RR, 1.43; 95% confidence interval, 1.15–1.78; $p < .01$), labor induction (RR, 1.16; 95% CI, 1.05–1.27; $p < .01$), chorioamnionitis (RR, 1.43; 95% CI, 1.22–1.69; $p < .001$), cesarean delivery (RR, 1.09; 95% CI, 1.04–1.14; $p < .001$), premature rupture of membranes (RR, 1.34; 95% CI, 1.20–1.50; $p < .001$), antepartum hemorrhage (RR, 1.36; 95% CI, 1.13–1.64; $p < .001$), and postpartum hemorrhage (RR, 1.30; 95% CI, 1.13–1.49; $p < .001$). After adjustment for socioeconomic and hospital characteristics, the risk for gestational diabetes, preeclampsia and eclampsia, placenta previa, and chorioamnionitis remained unexplained.

- Panko TL, Cuculick J, Albert S, Smith LD, Cooley MM, Herschel M, Mitra M, McKee MM. Deaf women's experiences of pregnancy and perinatal healthcare access: A qualitative study. *BJOG*. Published online September 26, 2022.

Semi-structured interviews with 45 deaf mothers about access to perinatal information and resources, relationships with healthcare providers, including communication access, and experience with the healthcare system throughout the pregnancy. Barriers and facilitators emerged under three major themes: (1) communication accessibility, (2) communication satisfaction, and (3) healthcare provider and team support. The most common challenges involved choosing healthcare providers, inconsistent communication access, and difficulty accessing health information. However, when deaf women were able to use American Sign Language (ASL) interpreters, they had more positive pregnancy and birth experiences. Additionally, self-advocacy served as a facilitator to more positive experiences.

NIH R21 HD081309. "Prevalence and Outcomes of Pregnancy in Women with Disabilities." PI: Willi Horner-Johnson. 2014–2017.

- Darney BG, Biel FM, Quigley BP, Caughey AB, Horner-Johnson W. Primary cesarean delivery patterns among women with physical, sensory, or intellectual disabilities. *Womens Health Issues*. 2017;27(3):336–344.

Retrospective cohort study using linked birth certificate and hospital discharge data for all deliveries in California from 2000–2010 (n = 4,610,955). Logistic regression analyses was used to examine the association of disability (identified via ICD-9 codes) and primary cesarean delivery, controlling for sociodemographic characteristics and comorbidities, and stratified by parity. The proportion of primary cesarean in women with disabilities was twice that in women without disabilities (32.7% vs. 16.3%; p < .001; adjusted odds ratio, 2.05; 95% confidence interval, 1.94–2.17). The proportion of deliveries by cesarean was highest among women with physical disabilities due to injuries compared with women without disabilities (57.8% vs. 16.3%; p < .001; adjusted odds ratio, 6.83; 95% confidence interval, 5.46–8.53).

- Horner-Johnson W, Biel FM, Darney BG, Caughey AB. Time trends in births and cesarean deliveries among women with disabilities. *Disabil Health J*. 2017;10(3):376–381.

Retrospective cohort study using linked vital records and hospital discharge data for all deliveries in California from 2000–2010 (n = 4,605,061). Women with potential disabilities were identified using ICD-9 codes. Descriptive statistics and visualizations were used to examine time patterns. Logistic regression analyses assessed the association between disability and primary cesarean delivery, stratified by year. Among all women giving birth, the proportion with a disability increased from 0.27% in 2000 to 0.80% in 2010. Women with disabilities had significantly elevated odds of primary cesarean delivery in each year, but the magnitude of the odds ratio decreased over time from 2.60 (95% confidence interval [CI], 2.25–2.99) in 2000 to 1.66 (95% CI, 1.51–1.81) in 2010.

- Horner-Johnson W, Kulkarni-Rajasekhara S, Darney BG, Dissanayake M, Caughey AB. Live birth, miscarriage, and abortion among U.S. women with and without disabilities. *Disabil Health J*. 2017;10(3):382–386.

Analysis of pooled Medical Expenditure Panel Survey (MEPS) data from Panels 1–11 (covering years 1996–2007), which included a Pregnancy Detail module assessing outcomes for women who were pregnant during panel participation. Among women with a recorded pregnancy outcome, women with disabilities were less likely to have live births (80.8% of women with basic action difficulties and 75.3% of women with complex activity limitations versus 85.0% of women without disabilities), but differences related to disability were not significant when adjusting for covariates. Women with complex activity limitations were significantly more likely to report miscarriages, even when controlling for covariates. Disability was not significantly associated with abortion in the adjusted analysis.

- Horner-Johnson W, Biel FM, Caughey AB, Darney BG. Differences in prenatal care by presence and type of maternal disability. *Am J Prev Med.* 2019;56(3):376–382.

Retrospective cohort study using linked maternal and infant hospital discharge and birth certificate data for all births in California from 2000–2012 (n = 6,745,201). A comparison was conducted between women with and without disabilities on trimester of prenatal care initiation and number of prenatal care visits. Women with intellectual or developmental disabilities (IDD) or with limited hearing had significantly higher relative risk of delaying prenatal care initiation until the second or third trimester (IDD: adjusted relative risk [RR] = 1.21, 95% confidence interval [CI], 1.09–1.33; hearing: adjusted RR = 1.11, 95% CI, 1.02–1.21). Women with limited hearing or vision or IDD had a higher risk of receiving fewer prenatal visits than recommended, compared with women without disabilities. Delays in receipt of prenatal care and low numbers of prenatal care visits may contribute to the poorer birth outcomes that have been observed previously in these groups.

- Horner-Johnson W, Dissanayake M, Wu JP, Caughey AB, Darney BG. Pregnancy intendedness by maternal disability status and type in the United States. *Perspect Sex Reprod Health.* 2020;52(1):31–38.

Cross-sectional analyses of data from the 2011–2013 and 2013–2015 waves of the National Survey of Family Growth. The sample included 5,861 pregnancies reported by 3,089 women. A higher proportion of pregnancies were unintended among women with disabilities than among women without disabilities (53% vs. 36%). Women with independent living disability had the highest proportion of unintended pregnancies (62%). In regression analyses, the odds that a pregnancy was unintended were greater among women with any type of disability than among women without disabilities and were also elevated among women with hearing disability, cognitive disability, or independent living disability.

- Dissanayake M, Darney BG, Caughey AB, Horner-Johnson W. Miscarriage occurrence and prevention efforts by disability status and type in the United States. *J Womens Health (Larchmt).* 2020;29(3):345–352.

2011–2015 National Survey of Family Growth data on women with at least one completed pregnancy within the past 5 years. The analytic sample included 3,843 women with 5,776 completed pregnancies within the past 5 years. Overall, 31.63% of women with disabilities and 21.83% of women without disabilities had had a miscarriage within the past 5 years. Women with disabilities were more likely than women without disabilities to receive recommendations

for bed rest to try to prevent a miscarriage. That difference is concerning because there is little evidence that bed rest is helpful, and it may increase risk of bone loss, muscle atrophy, and thrombus.

- Horner-Johnson W, Darney BG, Biel, FM, Caughey AB. Prolonged postpartum length of hospital stay among women with disabilities. *Disabil Health J.* 2020;13(4):100934.

Retrospective cohort study using linked maternal and infant hospital discharge and birth certificate data for all births in California from 2000–2012 (n = 6,745,201). Multivariable regression analyses were used to assess association of disability status and type with prolonged length of stay (>2 days for vaginal delivery or >4 days for cesarean) while controlling for covariates. Women with disabilities had significantly elevated adjusted odds of prolonged length of stay compared to women without disabilities (adjusted odds ratio [aOR] = 1.40; 95% confidence interval [CI], 1.32–1.49). Adjusted odds were highest for women with vision disabilities, followed by women with IDD and women with physical disabilities. Women with hearing disability had the lowest adjusted odds of prolonged length of stay.

- Biel F, Darney B, Caughey A, Horner-Johnson W. Medical indications for primary cesarean delivery in women with and without disabilities. *J Matern Fetal Neonatal Med.* 2020;33(20):3391–3398.

Retrospective cohort study of all nulliparous births in California from 2000–2012. Births were classified by whether women underwent a trial of labor or not and determined whether medical indications for cesarean delivery were present. Women with disabilities had lower odds of having a labored delivery, compared to women without disabilities (adjusted odds ratio [aOR] = 0.45; 95% confidence interval [CI], 0.41–0.49). In the subsample of unlabored cesarean deliveries, women with disabilities were less likely to have documented medical indications for cesarean delivery (aOR = 0.45; 95% CI, 0.41–0.50).

- Horner-Johnson W, Garg B, Darney BG, Biel FM, Caughey AB. Severe maternal morbidity and other perinatal complications among women with physical, sensory, or intellectual and developmental disabilities. *Paediatr Perinat Epidemiol.* 2022;36(5):759–768.

Retrospective cohort study using birth and death certificate data linked with hospital discharge data for all births in California from 2000–2012 (n = 5,787,090). In multivariable analyses, risk of severe maternal morbidity (SMM) for births to women with disabilities was nearly three times that for women without disabilities (relative risk [RR] = 2.84; 95% confidence interval [CI], 2.67–3.02). Proportion and risk of SMM were greatest for vision disability (793 per 10,000; RR = 4.04; 95% CI, 3.41–4.78). Secondary outcomes were also more common among women with disabilities. In particular, more than a third of births to women with IDD (37.4%) were complicated by mental health disorders (versus 2.2% for women without disabilities).

AHRQ K12 HS022981. “Oregon Patient Centered Outcomes Research K12 Program.” PI: Jeanne-Marie Guise. 2014–2019.

- Horner-Johnson W, Moe EL, Stoner RC, Klein KA, Edelman AB, Eden KB, Andresen EM, Caughey AB, Guise JM. Contraceptive knowledge and use among women with intellectual, physical, or sensory disabilities: A systematic review. *Disabil Health J.* 2019;12(2):139–154.

Search of MEDLINE, PsycINFO, the Cochrane Library, CINAHL, and ERIC databases from inception through December 2017 following PRISMA guidelines for identifying and reviewing studies. The review included 54 unique studies assessing contraceptive knowledge, contraceptive use, and interventions to improve knowledge and/or use. Women with intellectual disabilities (ID) and those who were deaf or hard of hearing had lower knowledge of contraceptive methods than women without disabilities. Estimates of contraceptive use varied widely, with some evidence that women with disabilities may use a narrower range of methods. Five of six studies evaluating educational interventions to increase contraceptive knowledge or use reported post-intervention improvements.

- Horner-Johnson W, Klein KA, Campbell J, Guise JM. Experiences of women with disabilities in accessing and receiving contraceptive care. *J Obstet Gynecol Neonatal Nurs.* 2021;50(6):732–741.

Four focus groups organized by disability type: physical disability, intellectual and developmental disability (IDD), blind or low vision, and deaf or hard of hearing. Focus group transcripts were analyzed using content analysis. Participants identified challenges to obtaining high-quality contraceptive care in three main areas: accessibility and accommodations, clinician attitudes, and health insurance. Participants with physical disabilities encountered inaccessible clinic rooms and examination tables, and participants with sensory disabilities or IDD described inaccessible clinic forms and information. Participants from multiple disability groups described negative attitudes of health care providers and health insurance limitations.

- Horner-Johnson W, Klein KA, Campbell J, Guise JM. “It would have been nice to have a choice”: Barriers to contraceptive decision-making among women with disabilities. *Womens Health Issues.* 2022;32(3):261–267.

Focus groups with reproductive age adult women (aged 18–45 years), grouped by disability type (physical disability, intellectual and developmental disabilities, blind or low vision, and Deaf users of American Sign Language). Focus group transcripts were analyzed using content analysis. Barriers to informed contraceptive decision-making emerged in five main thematic areas: (1) lack of information in accessible formats, (2) incomplete information about contraceptive side effects, (3) limited clinician knowledge and relevant research specific to the care of women with disabilities, (4) taboos around discussing sexual activity, and (5) limited opportunities for shared contraceptive decision-making.

Satisfaction with Care and Communication with Clinicians

AHRQ R01 HS10223. “Quality of Care and Service Use for Persons with Disabilities.” PI: Lisa I. Iezzoni. 1999–2002.

- Iezzoni LI, Davis RB, Soukup J, O’Day B. Satisfaction with quality and access to health care among people with disabling conditions. *Int J Qual Health Care.* 2002;14(5):369–381.

Analyses of 1996 Medicare Current Beneficiary Survey. Persons with disabilities generally had significantly higher adjusted odds of dissatisfaction. For elderly persons with any major disability, the adjusted odds ratios (95% confidence interval) of dissatisfaction were 3.2 (2.4–4.3) for

overall quality; 3.2 (2.2–4.6) for access to specialists; 4.4 (3.1–6.4) for follow-up; and 4.2 (3.1–5.7) for ease of getting to doctors.

- lezzoni LI, Davis RB, Soukup, O’Day B. Quality dimensions that most concern people with physical and sensory disabilities. *Arch Intern Med*. 2003;163(17):2085–2092.

Analyses of 1996 Medicare Current Beneficiary Survey. Roughly 98% of people with and without disabilities believed their physicians were competent and well trained. But statistically significantly more people with disabilities reported dissatisfaction with care for 10 of the 12 quality dimensions. Persons reporting any major disability were more likely to be dissatisfied with physicians completely understanding their conditions (adjusted odds ratio [AOR], 2.4; 95% confidence interval [CI], 1.9–3.1), physicians completely discussing patients’ health problems (AOR, 2.4; 95% CI, 1.9–2.9), physicians answering all patients’ questions (AOR, 2.3; 95% CI, 1.7–3.1), and physicians often seeming hurried (AOR, 1.6; 95% CI, 1.4–1.9).

- lezzoni LI, O’Day BL, Killeen M, Harker H. Communicating about health care: observations from persons who are deaf or hard of hearing. *Ann Intern Med*. 2004;140(5):356–362.

Analyses of four semi-structured group interviews: two conducted in American Sign Language and two using Communication Access Realtime Translation. Concerns coalesced around six broad themes: conflicting views between physicians and patients about being deaf or hard of hearing; different perceptions about what constitutes effective communication (such as lip reading, writing notes, and sign language interpreter); medication safety and other risks posed by inadequate communication; communication problems during physical examinations and procedures; difficulties interacting with office staff; and problems with telephone communication, such as lengthy message menus.

- O’Day BL, Killeen M, lezzoni LI. Improving health care experiences of persons who are blind or low vision: suggestions from focus groups. *Am J Med Qual*. 2004;19(5):193–200.

Analyses of eight interviews with experts and two focus groups with 19 persons, all of whom are blind or have low vision. Barriers fell into four broad categories: basic respect, including concerns about physicians thinking they cannot participate fully in their own care; communication barriers, including difficulties interacting with physicians and office staff; physical access barriers, including difficulties getting to and around physicians’ offices; and information barriers, including receiving written materials in inaccessible formats (e.g., not in Braille, large print, or audiotape).

- O’Day BL, Killeen MB, Sutton J, lezzoni LI. Primary care experiences of people with psychiatric disabilities: barriers to care and potential solutions. *Psychiatr Rehabil J*. 2005;28(4):339–345.

Analyses from 16 focus group participants with psychiatric disabilities. Participants cited (a) difficulty identifying a primary care physician with good empathic and communication skills, (b) physicians’ misunderstanding of the nature of psychiatric disability, (c) inadequate information about the side effects of psychotropic medications, and (d) costs due to inadequate insurance coverage.

NIH K08 AG029527. “Continuity of Care and the Health of Older Adults.” PI: Nancy Pandhi. 2009–2013.

- Pandhi N, Schumacher JR, Barnett S, Smith MA. Hearing loss and older adults' perceptions of access to care. *J Community Health*. 2011;36(5):748–755.

Analyses of data from the Wisconsin Longitudinal Survey (WLS; R01 AG009775), 2003–2006 wave (n = 6,524). Access difficulties/delays and satisfaction by respondents' hearing status (hard-of-hearing or not) were compared using multivariate regression. Data collection was via telephone interviews. Hard-of-hearing individuals comprised 18% of the sample. After adjustment for potential confounders, hard-of-hearing individuals were more likely to report difficulties in accessing healthcare (odds ratio = 1.85; 95% confidence interval, 1.19–2.88). The prevalence of hearing loss in this data is low, and findings from a telephone survey likely underestimate the magnitude of access difficulties experienced by hard-of-hearing older adults.

Financial Access to Care

AHRQ R01 HS015941-01A1. "How Health Insurance Status Affects Persons with Disabilities." PI: Lisa I. Iezzoni. 2006–2010.

- Pizer S, Frakt A, Iezzoni LI. Uninsured adults with chronic health conditions or disabilities: gaps in public health insurance programs. *Health Aff (Millwood)*. 2009;28(6):w1141–w1150.

Analyses of Medical Expenditure Panel Survey data from 2000–2005. Among nonelderly U.S. adults (ages 25–61), uninsurance rates increased from 13.7% in 2000 to 16.0% in 2005. Despite the existence of public insurance programs, rates remained high for low-income people reporting serious health conditions (25% across years) or disabilities (15%). Residents of southern states had even higher rates (32% with health conditions, 22% with disabilities). Those who did not belong to a federally mandated Medicaid eligibility category were about twice as likely as others to be uninsured overall, and uninsurance among this group increased more rapidly over time.

- Iezzoni LI, Frakt AB, Pizer SD. Uninsured persons with disability confront substantial barriers to health care services. *Disabil Health J*. 2011;4(4):238–244.

Analyses of Medical Expenditure Panel Survey data from 2000–2006. Uninsured persons with disabilities reported barriers significantly ($p = .001$) more often than did individuals without disabilities: 36.0% of uninsured persons with disabilities reported being unable to get necessary medical care, compared with 9.5% of uninsured, nondisabled persons; and 26.9% of uninsured persons with disabilities reported being unable to get necessary medications, compared with 5.3% of uninsured individuals without disabilities. Having a cognitive impairment produced the largest adjusted odds ratio (AOR) of reporting any access barrier (AOR, 1.64; 95% confidence interval [CI], 1.44–1.87), while having lower body functional limitations or hearing deficits also produced relatively high AORs (AOR, 1.47; 95% CI, 1.32–1.65 and AOR, 1.48; 95% CI, 1.11–1.98, respectively).

Rural Residents with Disabilities

AHRQ R01 HS10223. "Quality of Care and Service Use for Persons with Disabilities." PI: Lisa I. Iezzoni. 1999–2002.

- Iezzoni LI, Killeen M, O'Day BL. Rural residents with disabilities confront substantial barriers to obtaining primary care. *Health Serv Res*. 2006;41(4 Pt 1):1258–1275.

Analyses of focus group interviews with 35 rural residents in Massachusetts and Virginia. Interviewees reported substantial difficulties finding physicians who understand their disabilities and sometimes feel that they must teach their local doctors about their underlying conditions. Interviewees described needing to travel periodically to large medical centers to get necessary specialty care. Many are poor and are either uninsured or have Medicaid coverage, complicating their searches for willing primary care physicians. Because many cannot drive, they face great difficulties getting to their local doctor and especially making long trips to urban centers. Available public transportation often is inaccessible and unreliable. Physicians' offices are sometimes located in old buildings that do not have accessible entrances or equipment. Based on their personal experiences, interviewees perceive that rural areas are generally less sensitive to disability access issues than urban areas.

Barriers to Care, Failures to Accommodate Disability, and Ableist Attitudes

NIH R21 HD068756-01A1. "Pregnancy Experience of Women with Physical Disabilities." PI: Lisa I. Iezzoni. 2012–2013.

- Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Physical accessibility of routine prenatal care for women with mobility disability. *J Women's Health (Larchmt)*. 2015;24(12):1006–1012.

Qualitative analyses of telephone interviews with 22 women with significant mobility difficulties who had delivered babies within the prior 10 years. Some women's obstetricians had height-adjustable examination tables, which facilitated transfers for physical examinations. Other women had difficulty transferring onto fixed-height examination tables and were examined while sitting in their wheelchairs. Family members and/or clinical staff sometimes assisted with transfers; some women reported concerns about transfer safety. No women reported being routinely weighed on an accessible weight scale by their prenatal care clinicians. A few were never weighed during their pregnancies.

NIH R01 HD091211-01A1. "Surveying Physicians to Understand Health Care Disparities Affecting Persons with Disabilities and Identify Approaches to Improve Their Care." PI: Lisa I. Iezzoni. 2018–2022.

- Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297–306.

Nationwide survey of physicians in seven specialties caring for adult outpatients. Among participants, 82.4% reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7% of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5% strongly agreed that they welcomed patients with disability into their practices, and 18.1% strongly agreed that the health care system often treats these patients unfairly.

- Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Donelan K, Agaronnik ND, Lagu T, Campbell EG. Use of accessible weight scales and examination tables/chairs for patients with significant mobility limitations by physicians nationwide. *Jt Comm J Qual Patient Saf*. 2021;47(10):615–627.

Nationwide survey of physicians in seven specialties caring for adult outpatients. Among those reporting routinely recording patients' weights (n = 399), only 22.6% (standard error [SE] = 2.2)

reported always or usually using accessible weight scales for patients with significant mobility limitations. To determine weights of patients with mobility limitations, 8.1% always, 24.3% usually, and 40.0% sometimes asked patients. Physicians practicing ≥ 20 years were much less likely than other physicians to use accessible weight scales: odds ratio (OR) = 0.51 (95% confidence interval [CI] = 0.26–0.99). Among participants seeing patients with significant mobility limitations (n = 584), only 40.3% (SE = 2.2) always or usually used accessible exam tables or chairs.

- lezzoni LI, Rao SR, Ressalam JR, Bolcic-Jankovic D, Campbell EG. Incidence of accommodations for patients with significant vision limitations in physicians' offices in the US. *JAMA Ophthalmol.* 2022;140(1):79–84.

Nationwide survey of physicians in seven specialties caring for adult outpatients. Physicians' accommodation performance was assessed based on whether they always or usually described the clinic space and always or usually provided printed material in large font. Only 48 physicians (9.1%; 95% confidence interval [CI], 6.6–12.3) provided both accommodations (always or usually describing clinic spaces and providing large-font materials), while 267 (60.2%; 95% CI, 55.3–65.0) provided neither of these accommodations. Although 62.8% (95% CI, 57.5–67.8; n = 245) of non-ophthalmologists did not provide either accommodation, 29.3% (95% CI, 20.1–40.7; n = 22) of ophthalmologists also did not do so; only 24.0% (95% CI, 15.6–35.0; n = 18) of ophthalmologists provided both accommodations, compared with 8.4% (95% CI, 5.4–12.7) of other physicians.

- lezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik N, Lagu T, Pendo E, Campbell EG. US physicians' knowledge about the Americans with Disabilities Act and accommodation of patients with disability. *Health Aff (Millwood).* 2022;41(1):96–104.

Nationwide survey of physicians in seven specialties caring for adult outpatients. Among survey participants, 35.8% reported knowing little or nothing about their legal responsibilities under the Americans with Disabilities Act (ADA), 71.2% answered incorrectly about who determines reasonable accommodations, and 68.4% felt that they were at risk for ADA lawsuits. Physicians who felt that lack of formal education or training was a moderate or large barrier to caring for patients with disability were more likely to report little or no knowledge of their responsibilities under the law and were more likely to believe that they were at risk for an ADA lawsuit.