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OVERVIEW

Advancing Health Equity And Reducing Health Disparities For People With Disabilities In The United States

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ABSTRACT Definitions of *disability* have evolved over time. Consistent with the biopsychosocial model used by the World Health Organization, we conceptualize disability as an interaction between a person's functional impairments or chronic health conditions and the physical and social environment. Having a disability is not synonymous with poor health, and maintaining and improving health is equally important for both people with and people without disabilities. In this article we review estimates of disability prevalence in the US and present evidence of differences in prevalence by race, ethnicity, and sexual orientation; health disparities by disability status and type of disability; and health disparities for people whose disability intersects with other forms of marginalization. We suggest policy changes to advance equity, reduce disparities, and enhance the health and well-being of all Americans with disabilities.

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Despite significant health disparities experienced by people with disabilities, their needs are poorly addressed and understood in health policy, research, and practice. Estimates of prevalence vary depending on the definition of *disability* and the survey methods, but the consensus is that rates of disability are increasing with the aging of the US population, rising rates of chronic conditions among the nonelderly population, and more recently the COVID-19 pandemic. More than three decades after the passage of the Americans with Disabilities Act (ADA), disabled Americans still face barriers to health care, lower quality of care, and disparate health outcomes, in addition to inequitable access to transportation, education, housing, employment, and other social determinants of health. Existing health, economic, and social policies further exacerbate these disparities.

In this overview article we discuss disability definitions and prevalence, and we identify subgroups with a higher prevalence of disability. We present evidence of health disparities by disability status and type, as well as health disparities among people whose disability intersects with other forms of marginalization, and we provide policy recommendations to advance health equity for all disabled Americans.

Defining Disability

Disability can be defined in many ways, depending on context. The definition chosen affects benefits eligibility, civil rights protections, prevalence estimates, social stigma, and personal identity.^{1–4} One report identified sixty-seven federal statutory definitions of *disability* alone.⁵

Although there is no single way to define *disability*, there are prevailing concepts. Historically, the medical model has been dominant.^{6,7} It

defines *disability* as an impairment or problem existing within the body or mind that can be identified by objective scientific or expert observations and ameliorated with the guidance or treatment of experts to help the person adapt and conform to the “normal” environment.^{3,7}

The social model challenges the medical model’s definition identifying disabled people as defective and disabled lives as inherently inferior to nondisabled lives.^{6,8} From a social-model perspective, disability occurs when a person with an impairment interacts with physical or social environments that do not take the full range of human body variation into consideration and are unaccommodating or hostile as a result. In the social model, disability is a social construct, and disabled people are an oppressed minority group with unique histories and perspectives.⁴⁻¹¹

Critics identify limitations in both the medical and social models.^{2,6,12} They argue that disability is both a social and an embodied phenomenon. There have been models that draw on aspects of both models, such as the interactive or biopsychosocial model used by the World Health Organization.¹³

For the purposes of this article, we adopt this third approach and conceptualize disability as an interaction between a person’s functional impairments or chronic health conditions and the physical and social environment. Although some people’s disabilities are the result of health problems, disability and health are distinct concepts. Having a disability is not synonymous with poor health, and maintaining and improving health are equally important for people with and without disabilities.

Challenges In Estimating Disability Prevalence

Administrative records, such as those collected during health care visits, are inadequate in identifying people with disabilities, as they do not capture the full conceptual definition of *disability*. Therefore, researchers use surveys to estimate the size and characteristics of the disability population. Surveys differ in how they identify disabled respondents, and none does so perfectly—a limitation that hinders understanding of health needs and experiences of people with disabilities, as well as their health outcomes.

During the first several decades that the National Health Interview Survey (NHIS) was conducted, it used questions about health- or impairment-related limitations in the performance of age-appropriate life activities, such as attending school, working, or taking care of personal and household needs, to identify peo-

ple with disabilities.¹⁴ Gradually, the NHIS moved away from this approach and, in 2019, adopted two measures of functional limitations developed by the Washington Group on Disability Statistics: the Short Set on Functioning (WG-SS), which asks about difficulty performing physical or cognitive tasks,¹⁴ and the Enhanced Short Set, which includes the Short Set along with additional questions to measure communication and mental health, as well as difficulties with cognitive tasks and a range of physical tasks broader than those measured by the Short Set. Either measure can be used to define a disability population, according to researcher preference.

In the early 2000s the Census Bureau introduced the annual American Community Survey (ACS). The ACS includes six questions, known as the ACS-6, about functional limitations to identify respondents with disabilities.¹⁵ This approach has been criticized because the questions fail to identify substantial portions of certain disability groups, such as people with mental health or intellectual disabilities.^{16,17} Nevertheless, the ACS disability questions have been adopted as a standard for federal health surveys,¹⁸ as mandated by Section 4302 of the Affordable Care Act (ACA). The Centers for Disease Control and Prevention (CDC) also adopted the ACS-6 in 2016 in its Behavioral Risk Factor Surveillance System (BRFSS).

As shown in exhibit 1, there is large variation in estimates of the disabled population from these surveys. For example, the proportion of working-age adults estimated as disabled varies from 6.3 percent (2019 NHIS using the Short Set measure) to 23.3 percent (2019 BRFSS). Even when the disability questions are the same, as is the case with the ACS-6 and the BRFSS, the population estimate can vary considerably because of survey context, mode of administration, and potential sampling bias, particularly with telephone-based surveys.

Regardless of survey or measure set, adults ages sixty-five and older have substantially higher disability rates than do working-age adults. Despite the greater prevalence in the sixty-five and older age cohort, however, a majority of the disabled population is younger than age sixty-five, as assessed by the measures shown in exhibit 1.

Differences In Prevalence By Race, Ethnicity, And Sexual Orientation

Among racial and ethnic groups, disability prevalence is highest among American Indian/Alaska Native populations and lowest among Asian populations (exhibit 2). Black populations have a slightly higher prevalence of disability than White populations, and the difference increases

EXHIBIT 1
Estimates of disability prevalence in the US from selected federal surveys, 2018–19

Type of disability measure used	Surveys				
	NHIS, 2018	NHIS, 2019	NHIS, 2019	ACS, 2019	BRFSS, 2019
No. of survey items on disability ^e	11	27	33	6	6
Estimate of the total disability population					
No. (1,000s)	45,992	29,535	38,897	43,281	— ^f
% of US population	14.2	9.3	12.3	13.2	— ^f
By age group (years)					
Younger than age 18					
No. (1,000s)	6,869	6,875	6,875	3,191	— ^f
% of US population	9.4	10.5	10.5	4.4	— ^f
Ages 18–64					
No. (1,000s)	21,948	12,477	20,178	21,177	43,884
% of US population	11.1	6.3	10.2	10.5	23.3
Ages 65+					
No. (1,000s)	17,175	10,183	11,844	18,913	22,133
% of US population	33.5	19.1	22.2	35	42.6

SOURCE Authors' tabulations of data from the National Health Interview Survey (NHIS), 2018–19; American Community Survey (ACS), 2019 (six questions on disability, or ACS-6); and Behavioral Risk Factor Surveillance System (BRFSS), 2019. **NOTES** The NHIS and BRFSS exclude people living in institutions, such as long-term care facilities. The ACS includes both people living in institutions and people living in community settings. ^aA limitation in the performance of age-appropriate life activities, such as attending school, working, or meeting personal and household needs. ^bDefined according to the Washington Group Short Set on Functioning (WG-SS), developed by the Washington Group on Disability Statistics to measure difficulties in physical and cognitive tasks. ^cDefined according to the WG-SS Enhanced, developed by the Washington Group on Disability Statistics; includes the WG-SS along with additional questions to measure communication and mental health, as well as difficulties with cognitive tasks and a range of physical tasks broader than those measured by the WG-SS. For respondents younger than age 18, no additional questions were included. ^dDefined as difficulties with physical and cognitive tasks. ^eNumber of distinct survey questions on disability used for adults, children, or both. ^fThe BRFSS collects data from people ages 18 and older only.

with age adjustment. Unadjusted disability prevalence among Latino/a populations and Native Hawaiian/Pacific Islander populations is significantly lower than among White populations, but these differences disappear in the age-adjusted data.

Bisexual, transgender, and gender-nonconforming people also have a higher prevalence of disability than heterosexual cisgender people.¹⁹ Analysis of survey data from one state found that age-adjusted disability rates were significantly greater among gay, lesbian, and bisexual people than among heterosexual people.^{20,21} Data from a recent national survey on disability found higher rates of mental and psychiatric disabilities and intellectual and developmental disabilities among LGBTQI+ respondents, as well as greater prevalence of multiple disabilities, compared with heterosexual cisgender respondents.²²

Health Disparities By Disability Status And Type Of Disability

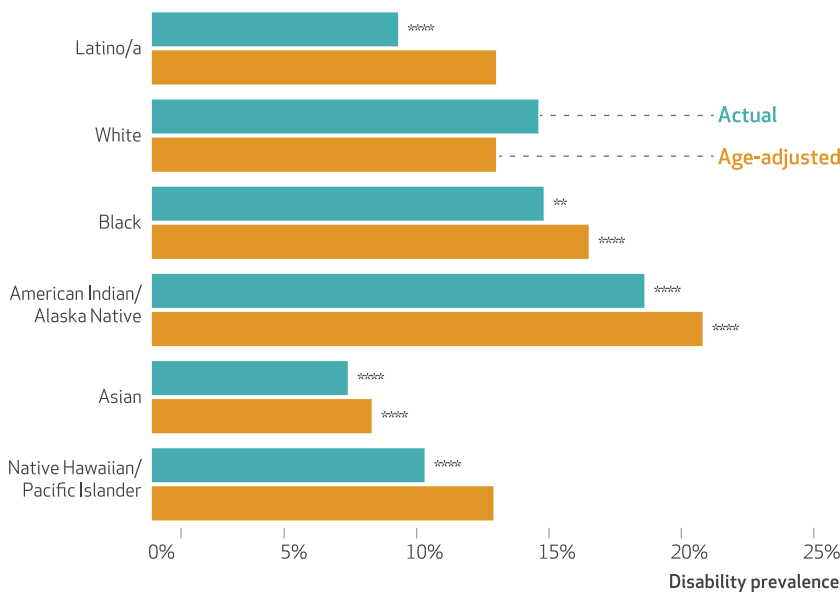
The phrase “health disparity” refers to adverse health differences affecting marginalized groups,

arising from systemic factors that lead to social disadvantage.²³ Health disparities are an equity issue and reflect both gaps in the quality of care received and broader patterns of injustice within society.²⁴ Work on health disparities has largely focused on racial and ethnic minorities, but people with disabilities are increasingly recognized as a health disparity population.²⁵ For example, through the *Healthy People 2030* initiative, the Department of Health and Human Services has designated people with disabilities as a health disparity population.²⁶ A challenge in identifying health disparities affecting disabled people is that some disabling conditions do inevitably lead to poorer health, regardless of individual circumstances, whereas in other instances, poorer health may be attributable to economic and social inequities such as barriers to health care access, thereby being accurately described as health disparities.¹ Disentangling cause and effect in attributing and addressing these differences is an ongoing challenge.²⁷

People with disabilities are more likely to report poor health and experience higher rates of chronic health conditions than nondisabled people. Data published in 2012 and 2015 indicate

EXHIBIT 2

Disability prevalence in the US, by race and ethnicity, actual and age-adjusted, 2019



SOURCE Authors' tabulations of data from the American Community Survey, 2019. **NOTES** Age-adjusted rates were calculated by applying the disability prevalence for each racial and ethnic group in 5-year age categories to the age distribution of the total population. All race categories shown are non-Latino/a. The *p* values refer to differences in disability prevalence (actual and age-adjusted) between the White population and other racial and ethnic populations. ***p* < 0.05 *****p* < 0.001

that disabled adults were more likely to experience chronic conditions such as cardiac disease, diabetes, higher weight, and asthma and to lack emotional support.^{28,29} They were also more likely to experience both injuries and intimate partner and interpersonal violence, according to studies published in 2015 and 2016.^{30,31}

Disabled women are more likely than their nondisabled peers to have chronic health conditions and to describe their general health as fair or poor.²¹ Women with disabilities have lower rates of breast and cervical cancer screening compared with nondisabled women, and disabled women with circulatory or respiratory conditions have higher rates of breast cancer mortality than women without disabilities.³²

Limited research identifies differences in health status and outcomes based on type of disability.³³ One study published in 2013 found that people with multiple disabilities had worse health outcomes and that people with hearing disabilities fared better on most outcomes than people with vision, physical, or cognitive disabilities.³⁴ Another study published in 2019 found that adults with intellectual disabilities or autism were more likely to report comorbidities, including poor mental health, than adults with other disabilities.³⁵

Disability-related health disparities have come into sharp focus during the COVID-19 pandemic.

As of January 2022 an estimated 200,000 nursing home residents had died of the disease, constituting roughly one-quarter of all COVID-19 deaths in the US.³⁶ People with intellectual and developmental disabilities were also disproportionately affected, having higher case-fatality rates than the general population, especially for those in residential settings.^{37,38} Recent statements from the CDC that postvaccination mortality is largely confined to people with multiple comorbidities³⁹ imply that the disability population is also experiencing disproportionate mortality.

Health Disparities And Intersectionality Among People With Disabilities

Health disparities among people with disabilities are affected by other forms of marginalization. The self-reported health status of disabled people has been found to vary across racial and ethnic groups.⁴⁰ Black and Latino/a adults with intellectual and developmental disabilities were more likely to report fair or poor physical and mental health compared with their White peers in a study published in 2016.⁴¹ Adults with mobility limitations who are members of racial or ethnic minority groups were more likely to report that their health was worse than a year ago and more likely to experience depression and to have diabetes, hypertension, or vision impairment than White people with mobility impairments in a study published in 2008.⁴²

Gender identity and sexual orientation also are factors in health disparities among people with disabilities. LGBTQI+ people with disabilities are more likely to report diminished health-related quality of life, including poor physical and mental health, than their non-LGBTQI+ peers with disabilities.²² Variations in the rates of poor health and chronic health conditions among disabled people with additional marginalized identities suggest that these disparities are associated with systemic issues related to multiple forms of oppression.²¹

Policy Changes To Advance Health Equity And Reduce Disparities

In this section we recommend policy changes to advance equity and reduce disparities for all people with disabilities in the US.

EXPANDING ACCESS TO HEALTH COVERAGE Access to health insurance coverage is key to reducing health disparities that can be attributed to cost and access to health care. Although public programs such as Medicaid serve a subset of disabled people, many other people with disabil-

Disability-related health disparities have come into sharp focus during the COVID-19 pandemic.

ities have long faced barriers to health coverage, including lack of affordability and preexisting condition exclusions. Through increased regulation of private coverage, subsidized premiums, and expansion of Medicaid eligibility, the ACA enabled many disabled people to overcome these barriers. Uninsurance declined significantly among disabled people after the ACA's provisions went into effect.⁴³ In addition, the proportion of disabled people who delayed or did not get care because of cost fell significantly. Even so, barriers to care remain.^{43,44} A single-payer system would provide a promising solution by eliminating financial barriers to care across the board. Medicaid expansion in the states that have thus far not expanded their Medicaid programs could also go a long way toward removing financial barriers for at least a subset of low-income people with disabilities. However, lack of political consensus and concerns about cost currently limit progress toward both of these potential solutions.⁴⁵

EXTENDING MEDICAID BUY-IN PROGRAMS A new approach to Medicaid buy-in programs could offer a viable alternative to these options. Depending on the state, disabled people whose work income renders them ineligible for Medicaid can participate in a “buy-in” program that involves paying premiums to enroll in Medicaid. Forty-five states offer such programs, which differ from broader Medicaid buy-in programs that may be used to expand Medicaid eligibility authorized under the ACA that do not necessarily include a disability requirement.⁴⁶ However, most of the narrower, disability-focused buy-in programs have very low income and asset limits that would exclude all but low-wage or part-time workers. As a result, many people with disabilities remain in poverty so that they can obtain health coverage for services not covered by private insurance, such as personal assistance services.⁴⁷ A small number of states, such as Massachusetts and Arkansas, offer Medicaid buy-in programs with no income or asset limits; these programs advance equity and reduce dis-

parities by empowering disabled people to participate fully in the workforce without fear of losing essential services or becoming impoverished.⁴⁷ Congress should enact legislation that provides states with enhanced federal reimbursement as an incentive to offer Medicaid buy-in programs to people with disabilities without income and asset limits. Premiums, additional tax revenues, and reduced participation in other government programs resulting from increased employment could help offset the cost of these programs.⁴⁷

EXPANDING ACCESS TO HOME AND COMMUNITY-BASED SERVICES Although Medicaid has long paid for institutional services, the program first paid for home and community-based services in the 1980s. In its 1999 landmark decision in *Olmstead v. L. C.*, the United States Supreme Court interpreted the integration mandate contained in the ADA to mean that states must take an evenhanded approach to providing care in community settings and institutions instead of limiting services to institutional care.⁴⁸ By making enhanced federal reimbursement available to states that increase access to home and community-based services and establishing a state plan option [Section 1915(i)] to enable states to provide these services to people whose disabilities are not severe enough to warrant institutional care, the ACA reduced the “institutional bias” that had long been a major feature of Medicaid long-term services and supports programs.^{49,50} There is evidence that a gradual rebalancing of community versus institutional services can lead to reduced costs⁵¹ and that unmet need for home and community-based services leads to negative health and community living outcomes.⁴⁹

Despite this progress, access to home and community-based services varies substantially from state to state,⁵⁰⁻⁵² and access to community-based long-term services and supports remains elusive for people ineligible for Medicaid but not wealthy enough to pay the high costs. A Medicare home and community-based services benefit would help address that gap, as would a universal public long-term services and supports insurance program, but concerns about financing have historically been barriers to adoption of these measures.⁵³

EXPANDING THE SCOPE OF COVERED SERVICES Definitions of *medical necessity* in public programs and private insurance, as well as the Medicare “homebound” requirement, lead to unmet health care needs and undermine the ADA's goal of community integration.^{54,55} Medicare's definition of *medical necessity* emphasizes diagnosis and treatment, and the homebound requirement limits reimbursement for Medicare home health services to those needed to function solely at

home, thereby precluding coverage of services primarily needed for people with disabilities to participate in community life and putting them at risk for social isolation, which has been shown to have deleterious effects on well-being.⁵⁶ *Medical necessity* definitions used by state Medicaid agencies and private insurers vary, and they likewise generally have the effect of restricting access to services for people with disabilities. A few state Medicaid programs, however, have definitions that are consistent with the goal of community integration for people with disabilities; Delaware's definition, for example, refers to the aim of "attain[ing] or retain[ing] independence, self-care, dignity, self-determination, personal safety, and integration into all natural family, community, and facility environments and activities."⁵⁷ Adoption of this or similar language in other state Medicaid programs, as well as in Medicare and private insurance, would help advance the widespread social integration and well-being of people with disabilities.

PURSuing INTEGRATED CARE PROGRAMS Challenges to community integration for people with disabilities also may be addressed through innovative integrated care programs for Medicaid recipients being pioneered by many states such as Massachusetts; these programs often feature flexibility in coverage of services beyond the usual bounds of the Medicare and Medicaid programs through the use of strategies such as care coordination and person-centered planning.^{58,59}

FOSTERING RESEARCH TO INFORM POLICY An important step in advancing policies to reduce disparities and achieve equity would be to designate people with disabilities as a health disparity population under the Minority Health and Health Disparities Research and Education Act of 2000.^{60,61} This designation is long overdue and would foster research to provide the evidence

Long-standing systemic factors undermine the full participation of many disabled people in US society.

base for policies to improve the health and well-being of all people with disabilities and reduce disparities.

Conclusion

Despite the hope that the ADA's nondiscrimination provisions would eliminate barriers to health care for disabled people, they continue to face deep and sustained inequities in health and health care access. Although these widespread inequities were undoubtedly exacerbated by the COVID-19 pandemic, long-standing systemic factors undermine the full participation of many disabled people in US society and widen disparities among marginalized groups within the disability population. It is critical to officially recognize people with disabilities as a Health Disparity Population under federal law and pursue evidence-based policy changes to realize the ADA's goal of enhancing full participation, independence, inclusion, and equality of opportunity for all Americans with disabilities. ■

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