Charting Equality

Why Demographic Disability Data is Good for Everyone

by Mary Lou Breslin and Silvia Yee
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Disability Rights Education and Defense Fund (DREDF) is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities. Founded in 1979, DREDF works to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.

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The **National Health Law Program** (NHeLP) protects and improves access to health care for low-income and underserved people and works to advance health equity. We believe that everyone should have access to high quality, equitable health care and be able to achieve their own highest attainable standard of health. We enforce health care and civil rights laws; advocate for better federal and state laws and policies; train, support and partner with national, state and local health and civil rights advocates; and use strategic communications to achieve these goals.

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Introduction to Disability Data

There is a common perception that the health care system possesses a lot of information about people with disabilities. In a data-driven society, every time an individual with a disability or chronic condition needs health care, some new piece of data is generated and kept somewhere. But there is a big difference between the medical information that is generated when a disabled person receives healthcare or the insurance information needed for a coverage decision, and the demographic disability data that is mostly absent from federal, state, and private health care systems. Standardized demographic disability data collection, called for by the 2010 Affordable Care Act, is based on identification of functional limitations related to characteristics such as vision, hearing, mobility, cognition, and independent living. It allows for comparison of people with and without disabilities in relation to demographic, health, and social characteristics.[1]

In this brief, we look at what we mean by demographic disability data. We discuss some common myths and stereotypes that likely influence why government and health entities tend to overlook a need to collect demographic disability data. We explain why demographic disability data is needed, how it differs from medical or insurance information, and why it is important for proper medical and insurance assessments. We also look at current examples of providers, health systems, and states that are working to collect demographic disability data. And finally, we provide some recommendations for how relevant entities could begin to collect this information, which is critical for ensuring that people with disabilities receive equally effective healthcare.

What is Demographic Disability Data?

Data vs. Diagnosis, Health vs. Disability

It's worth taking a moment to understand what demographic disability information is not before we consider what it is. An individual's medical diagnosis does not provide demographic information about that individual or a basis for demographic analysis on the population of people with disabilities, or even people with the same diagnosis. Many health conditions and disabilities have a range of functional impacts that

develop over time or unpredictably or not at all. This is true of conditions that are present at birth, develop in childhood, or are acquired later in adulthood or older age. For example, people with conditions such as Down Syndrome or Traumatic Brain Injury or another specific diagnosis may or may not use a wheelchair, may or may not use a communication device, may or may not have intellectual or learning disabilities, and may or may not ultimately have a shorter lifespan. In another example, rheumatoid arthritis (RA), an autoimmune and inflammatory disease, might cause swelling in the finger joints of one person and functional quadriplegia in another, limiting their ability to stand or walk.[2] Because the diagnosis is the same for both people, the diagnostic code for RA alone won't reveal the extent of functional limitation that might affect their need for accommodations during clinical visits, while carrying out activities of daily living, or when engaging with the community. Perhaps most important, the diagnostic code alone does not allow health care systems to understand or distinguish how people with multiple marginalized identities, including disability, are individually and collectively affected by historically racist, ageist, and ableist social systems.

Following the development over time of disability-related research on a topic such as maternal health and pregnancy outcomes illustrates how diagnostic codes alone do not accurately capture disability or allow researchers and advocates to build on prior research. Disabled women are having children at approximately the same rate as non-disabled women.[3] At the same time, pregnant women with disability are at higher risk of poor outcomes than pregnant women without disability, but the lack of baseline and functional demographic disability data makes it difficult to identify the prevalence of that risk, how differences in type and severity of disability affect the risk, and how its magnitude may change according to other demographic differences among groups of disabled people who can become pregnant. Many years of studies, both focused on specific disabilities such as intellectual and developmental disabilities and across disability types, establish that women with disabilities are more likely to experience adverse maternal health outcomes than women without disabilities, and the studies primarily derive information on disability from diagnostic codes.[4] The medical specificity of diagnostic codes makes it easier to focus on a particular kind of disability but does not necessarily allow for analysis based on severity or length of disability. One study looking at fertility desires and intentions found that women with disabilities were about as likely as women without disabilities to desire babies but were about 7% less likely to intend to have a baby as women without disabilities; the depth of their

findings were only possible because of a switch from "only one broadly worded item" on disability to the six questions used on the American Community Survey (ACS, discussed further in Part III).[5]

All the maternal health studies reviewed here are essentially forced to derive disability information from diagnostic codes. However, one study revealed that pregnant women with disabilities self-reported a higher prevalence of disabilities through a national survey than in studies that relied only on diagnostic codes. This finding confirms that only a small number of disabled pregnant women are identified as such through diagnostic codes alone.[6] Undercounting the number of disabled pregnant women has implications for our ability to conduct research that correctly identifies this population, reveal the health and health care disparities they experience, and support preventive measures and other interventions that would improve pregnancy outcomes for pregnant persons with disabilities. Limitations in how we identify disability also deeply impact intersectional research findings. A recent study found that the average economic "cost" of having a child, as measured in labor and delivery-related charges, for non-Hispanic Black and Hispanic women with intellectual or developmental disabilities (IDD) was 27% and 51% higher, respectively, than the average cost for white women with IDD.[7] The disability component was derived from diagnostic codes in health records. If those same records had self-identified information about functional status and disability, further research could more accurately reflect the numbers of people with disabilities, include disabled people who are less likely to be accurately identified through diagnostic codes, and help unearth increased nuance about the impact of systemic intersectional health disparities.

For the same reasons, a diagnosis by itself cannot be a proxy for whether and how disability correlates with other population characteristics, such as education and employment levels, unhoused status, racial or ethnic groups, LGBTQI+ status, family

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status, or access to healthcare, for the purpose of research. Good research cannot be performed when researchers have not identified the population of people who have disabilities as a demographic category; instead, what usually happens is policy and lawmakers make a default assumption that the fact of a medical diagnosis *causes* poor health and life outcomes. The assumption can be so overwhelming that it overshadows the known impacts of other disparities experienced because of characteristics such as race, ethnicity, gender, sexual orientation, and gender identity.[8]

At the same time, health conditions and functional limitations can be inherent in a disabled person's life, but disability and health are separate and distinct categories. That is, people can have a disability and still experience good health. However, some people with disabilities still experience poorer health that reflects the impact of substantial health disparities experienced by disabled people.[9] Factors that contribute to health disparities include disadvantages stemming from their historic segregation and exclusion from education, jobs, transportation, and housing.[10] The legacy of these practices contributes to ongoing disability stigma and helps explain why some physicians have negative attitudes toward disabled patients and expect them to have a poor quality of life that is directly attributed to the presence of disability, even when people with disabilities themselves indicate that they have a good or excellent quality of life.[11] Assumptions about the ill health of people with disabilities also contribute to the enduring persistence of physical and procedural barriers to accessing care.[12] Furthermore, disabled people who are most affected by health and healthcare inequities and disparities can also be members of historically marginalized groups including communities of color, LGBTQI+ individuals, and older people who have endured the intertwined effects of structural racism, ableism, lower incomes, and other forms of exclusion and discrimination.[13]

Defining Disability and Its Relationship with Demographic Disability Data

The useful collection of any demographic data needs agreement on underlying terms and what needs measuring. Whether people are answering for themselves or someone else is checking a box, collected data will be inaccurate and can't be analyzed if everyone has a different concept of what is being asked.

Our understanding of demographic terms can rest on a wide range of "objective" and accepted characteristics. Age, for example, is almost always measured in solar calendar

years of life since birth and this is generally accepted as an objective measure in much of the world. There may be less agreement on how socially or politically constructed categorizations such as race, ethnicity, sexual orientation, and gender identity can or should be "objectively" defined. In the case of race and ethnicity, federal agency standards established by the Office of Management and Budget (OMB) emphasize the regional geographic origin of recognized people groups. [14]

A focus on disability can acknowledge how medical diagnoses shape an understanding of disability and still reject that tidy fit as ill-suited to the purposes of equitable care and understanding of disparity that motivate present-day health and healthcare data collection. The medical origin of disability is undoubtedly critical to diagnosis. It can impact the interpretation of symptoms and functional limitations, determine what treatments are administered when, and can be used to determine the prevalence of specific diagnoses and their medical outcomes. But linking health outcomes purely to information about the origin of disability confuses diagnosis and health. Demographic disability data, on the other hand, recognizes that people with disabilities are people seeking health care and not just ill patients. The multiple external barriers that disabled people face when they seek health care inevitably have a distinct impact on health outcomes that can be remediated *if disability is measured as a demographic*.

Demographic disability data, recognizes that people with disabilities are people seeking health care and not just ill patients.

This understanding that disability, too, is at least partially socially mediated informs the way disability as a demographic should be measured. The World Health Organization (WHO) in 2001 defined disability as "result[ing] from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support."[15] This construction recognizes that how an individual with functional limitation(s) interacts with the environment is the inflection point that determines if the person experiences unfettered social inclusion or is barred from participation, partially or completely.

The interaction between disability and environment informs an individual's experience whether the person is in good or bad health, or has other characteristics

associated with health disparities. For instance, an individual with a mental health disability receives poor health care if physicians dismiss her experiences of pain and fail to treat her symptoms because they question her perceptions. In another example, disability is backgrounded when a Deaf transgender person communicates effectively with their hearing health care practitioner using a Sign Language interpreter, but they experience discrimination due to their gender identity. Conversely, disability is in the foreground when a Black pregnant wheelchair user confronts a flight of stairs with no ramp to a prenatal healthcare clinic, and at the same time, disability can be backgrounded if the woman's experience with inaccessibility is overshadowed by well-documented maternal healthcare disparities experienced by Black women.[16]

This conception of disability acknowledges that illness is not an inevitable outcome of disability. Health disparities and poor health outcomes among disabled people frequently stem from complex external factors rather than the disability itself. If this fact is not accepted, it leads to bad data collection that locates disability entirely in the individual. If a health problem is deemed to lie solely in the individual, then society is absolved of coming up with strategies to ensure health equity and achieve better health outcomes for people with disabilities.

Defining Demographic Disability Data

For the purposes of this paper, we will use the following working definition of demographic disability data:

> Data about an individual's functional capacity that is maintained to a sufficient currency and with enough granularity and consistency to allow for both meeting the individual's accommodation needs and performing population health analyses that includes disability as a demographic characteristic.[17]

After defining demographic disability data, we need to consider how best to accurately capture demographic disability data in a way that accounts for a spectrum of functional limitations. Disabled people may be dissuaded from self-identifying as such due to the burden of social stigma and financial consequence of doing so, and the risk-benefit calculus can be especially stark among those with less visible disabilities. While an existing set of functional limitation questions has been validated

for use in Census tools (more fully discussed in Section IV), people with different disabilities as well as disabled persons who come from different cultural or socio-economic backgrounds may not be identified within the existing set. How questions about functional limitation are worded, and who is answering the question, deeply affects how they are understood. An early effort by a federally qualified health care center in California to modify their electronic health record to include accommodation needs found that some patients "interpreted the question about accommodation for a mobility limitation as an inquiry about transportation needs."[18] The reality that diverse people with disabilities can think and speak very differently about their own health conditions and limitations needs to be better considered. The National Institutes of Health has put admirable recent work into pulling together multi-disciplinary experts, including community advocates, to develop recommendations for how to best measure sex, gender identity, and sexual orientation.[19] An equally rigorous and up-to-date disability community inclusive expert investigation on a set of measures for disability would be welcome as a way to maximize the potential for capturing statistically significant disabled populations with intersecting characteristics while preserving deidentification. Nonetheless, the need for improved capture should not obscure the fact that existing census tools such as the ACS-6 have been in use since 2008.[20]

In this paper we make the case for adopting existing tools for collecting demographic disability data as soon as practicable, but simultaneously argue for ongoing work to improve the collection of demographic disability data. In doing so, we follow the example set by OMB's reworking in 2023 of its 1997 Race and Ethnicity Standards.[21]

The revisions undertaken in 2023 followed periodic OMB reviews of federal statistical standards "to ensure that they are keeping pace with changes in the population and evolving needs and uses for data" because "they seek to capture dynamic and fluid sociopolitical constructs."[22] The 2023 revision proposed separated out Middle Eastern and North African racial groups from the existing categorization of white and persons that self-identify as more than one race or ethnicity. This action would require a bridging of data obtained from the 1997 Race and Ethnicity Standards and the newer revised set, but OMB and many commenters, led by racial groups and advocates most directly affected by the change, considered the break in continuity worthwhile to obtain fuller responses from the public and greater accuracy of data. That same reasoning, including the importance of affected community involvement, applies to

future changes that may be made to disability data collection standards, such as those used by the census, but should not delay the swift incorporation of the existing disability questions in other data instruments.

Sources of Demographic Disability Data

Our current understanding of health disparities that affect disabled people comes primarily from federal and state population and health surveys. These sources provide the most consistent data over time about how many people in the United States have disability and their self-reported health status. Other sources of demographic data include health records and administrative forms that usually have some demographic data fields for race, ethnicity, age, sexual orientation, and gender identity that people can mark voluntarily. These granular administrative and health record data can provide a detailed picture of an individual's health status and changes in health conditions at the points of patient contact and at multiple times. However, most administrative forms and patient electronic health records (EHRs) do not have fields that disabled people can voluntarily select to identify themselves. Consequently, it isn't possible to know who is disabled from these records alone.[23]

The following chart provides an overview of these sources for demographic disability data and compares some of their key characteristics. It can serve as a guide throughout the remainder of this paper.

Data type	Examples	Has current disability questions	How collected	Useable to track patient accommodation	Useable for health disparity analysis	Based on ACS-6, WGSS, or another option
Federal Census	Decennial Census of entire U.S. population	No	Mandatory to answer, data protected	No	No	ACS-6 data used in place of direct data in Census after 2000[24]
Federal Surveys (Population Samples)	American Community Survey, National Health Interview Survey, Behavioral Risk Factor Surveillance System, Healthcare Cost and Utilization Project	Some do	Mandatory to answer if chosen, data protected	No	Yes	Mostly ACS-6,[25] though the National Health Interview Survey and a few others use WGSS
State Administered Surveys	California Health Interview Survey, New Jersey Behavioral Risk Factor Survey[26]	Mostly No	Core questions mandatory, data protected	No	Yes	A mix
Administrative Data	Databases compiled from Medicaid & Medicare applications, claims and encounter data, and patient equity and quality data	Mostly No	Voluntary self-report, data protected	Maybe	Yes	ACS-6+ where disability is included
Healthcare Eligibility and Encounter Data	EHRs, Managed Care databases,	Mostly No	Voluntary self-report, data protected if held by certain entities	Yes	Yes	ACS-6 + where disability is included

Surveys

Our current understanding of health disparities that affect disabled people comes mostly from federal and state population and health surveys. These sources provide the most consistent data over time about how many people in the United States have disability and their self-reported health status. Many of these population-based surveys measure disability by using six functional limitation questions that were incorporated into the U.S. Department of Health and Human Services Data Collection Standards in 2011 after the Affordable Care Act included disability as a bona fide health disparity demographic and adopted functional limitation questions for use in U.S. population health surveys.[27] The questions ask about hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent living difficulty.[28] The questions, referred to as the ACS-6 because of their initial use in the American Community Survey, have been in official use since 2008 and represent the minimum standard for federal population-based surveys in the United States.[29] Data from these surveys are being used widely for reporting disability prevalence and for facilitating analysis of population health, but they are inconsistently included in state health care surveillance efforts or regulatory requirements which cover the administration of Medicaid as well as private individual and small group insurance.[30]

American Community Survey Demographic Disability Questions

1. Are you deaf, or do you have serious difficulty hearing?

2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?

3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)

4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)

5. Do you have difficulty dressing or bathing? (5 years old or older)

6. 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)[31]

Administrative Data and the Electronic Health Record

Administrative data collected from health and health care-related documents such as intake forms, health records, benefits applications, and needs assessments, are rich sources of information that help analysts compare utilization, differences in care by various patient and community characteristics, quality outcomes, and other aspects of healthcare effectiveness across demographic populations. These granular administrative and health record data can provide a detailed picture of an individual's health status and changes in health conditions at the points of patient contact and at multiple points in time.

Few health systems, plans, and programs collect disability data as a distinct demographic field on administrative forms and EHR. Yet, without disability data from both administrative and electronic health records, it is virtually impossible for health care providers, health plans, public health organizations, and state and federal health care agencies to identify disabled patients enrolled in health care systems as a distinct, heterogeneous, demographic group. This failing directly affects the quality of health care that people with disabilities receive. It also prevents researchers from investigating the intertwined causes of health and health care inequities and disparities among people with multiple demographic identities, including disability. Moreover, the absence of this data also increases the difficulty of establishing that disabled people are subject to health and healthcare disparities caused by factors other than disability.

Over the past decade, as interoperability standards take increasing effect, the EHR has become especially important because it makes patient data readily available to healthcare providers in multiple locations and, in some situations, allows coordination of care across social service organizations. These records also enable rapid assessment of public health trends and threats, such as the COVID-19 pandemic that started in 2020. Analysts and researchers use EHRs to understand and measure real-time progress toward addressing injustices and identifying pathways to improving the quality of healthcare.[32]

Why Collect Demographic Disability Data

Disability Prevalence

Researchers and advocates working for disability data collection in healthcare have a saying, "Who counts depends on who is counted."[33] In other words, we can't improve what we can't measure. Yet health care and public health systems do not routinely collect demographic disability data even as over 64 million community-dwelling U.S. adults have a disability, representing almost 25 percent of the U.S. population.[34] The prevalence of disability is also increasing as the U.S. population ages and younger people are reporting increases in chronic conditions. The first baseline reason for collecting demographic disability data is to know the prevalence of people with disabilities since this directly affects the allocation of federal and state resources and access to government services, supports, and local programs used by people with disabilities.

While it might be currently possible to derive an estimate of how many people in the United States have a disability from just asking a single question, the resulting bare figure is highly likely to lead to undercounts and, without more, tells us very little. What are the housing needs of people with specific types of disabilities, and what kind of healthcare insurance do they have? How do their functional limitations affect their ability to work full-time? What impact do different functional limitations have on the receipt of preventive care by disabled people? What is their familial, educational, social, and economic context? What are their health care needs, and how does their access to state and federal resources differ? What is their racial/ethnic composition, how many are LGBTQI+, and critically, what are their experiences of health and health care access? These are all questions that cannot begin to be answered without a range of demographic information, including demographic disability information.

Not only do we need the bare minimum of identification – who has certain functional limitations – we ideally would have information such as when a disability was acquired and the level of functional impairment. These factors affect how an individual interacts with their environment. For instance, a person with a traumatic brain injury might have little or no difficulty walking while another person with the same diagnosis could be a functional quadriplegic who uses a motorized wheelchair. The wheelchair user could experience architectural, medical diagnostic equipment, and transportation

barriers to getting health care while the person with little or no mobility limitation likely does not face these barriers. Functional limitation information provides some level of detail on how and when health care barriers arise for disabled people and begins to tell us something about the barriers they likely encounter when seeking access to social determinants of health.

In addition to information on functional limitations, demographic disability data should also include information on chronic conditions, communication disabilities, mental health disabilities, and developmental disabilities. Recent research has noted the gaps that can arise when *only* functional disability questions are used.[35] People who self-identify with a range of significant chronic conditions, mental health disabilities, or developmental disabilities, do not necessarily respond affirmatively to questions that only ask about functional limitations with walking, seeing, thinking and concentrating, self-care, and so forth. As one author notes:

> If both function- and condition-specific questions are included in these surveys, data can be used more reliably by researchers, policy makers, and practitioners to track prevalence and types of disabilities, create more supportive services and environments, understand health disparities, and address risks. Mounting evidence suggests that understanding and tracking disability at the national level can be improved, and the addition of a small complement of disability questions seems like a reasonable charge.[36]

As a baseline, improving how we capture the prevalence of people with disabilities is fundamental to public health goals and fully including people with disabilities in resource allocation. Where we have tools such as the ACS-6 or the WGSS that focus on self-identification of functional limitation, we can still engage in thoughtful rigorous research on the most effective way to accurately solicit information on how people experience those limitations. In further sections, we discuss how to unlock the usefulness of demographic disability data to remove barriers and improve healthcare access, quality, and outcomes for disabled individuals.

Beyond Prevalence – Moving from Disability as an Outcome to Disability as a Demographic Factor

As discussed in Part II, the primary sources of information on people with disabilities are national surveys. These sources have limited use for both individuals and

populations of people with disabilities because they merely measure outcome; disability demographic data is also needed to facilitate and improve health care for people with disabilities. To unlock the potential of disability data, disability fields should also be collected within Electronic Health Records (EHRs) and administrative forms for three primary purposes:

1) To identify and consistently provide individual accommodations/policy modifications that are fundamental to ensuring that disabled people receive and benefit from healthcare that is at least as effective as that provided to people who do not have disability;

2) To identify health and health care disparities that disabled people experience, analyze their impact on health status, health outcomes, future health and longevity, and create interventions to address them, and;

3) To deepen understanding of interrelated disparities, including discrimination experienced by those with multiple demographic characteristics that include disability.

Each of these purposes is addressed in greater detail below.

Providing Accommodations that Ensure Equitable Care

The lack of administrative disability data in patient EHRs hinders planning, arranging, and providing legally required accommodations for disabled people that are necessary for care to be equitable. When care isn't equitable, health disparities can arise. The Rehabilitation Act of 1973 and the regulations enacted under it by the Department of Health and Human Services (HHS),[37] the Americans with Disabilities Act (ADA) of 1990,[38] and Section 1557 of the 2010 Affordable Care Act (ACA)[39] spell out in detail actions that health entities are required to take to prevent disability discrimination and ensure that disabled patients have full and equal access to services and programs. These include physically accessible buildings and facilities, including parking, paths of travel, and restrooms, accommodations for effective communication such as extended appointment time or American Sign Language (ASL) interpreters, and non-discriminatory policies and procedures, such as prohibiting a practitioner from refusing to treat someone with HIV infection.

Administrative data collected from health and health care-related documents can provide a detailed picture of an individual's health status and changes in health conditions at various points in time. However, as explained in Part II, diagnostic data alone can't provide an accurate picture of how functional limitations might affect delivery of health care. When disability information is missing in the EHR, frontline staff may not have access to a cue or trigger in the patient record telling them when and under what circumstances a patient needs an accommodation. Consequently, providers cannot plan adequately for an upcoming visit, for instance arranging for extended exam time to ensure effective communication for someone with a speech limitation or providing a large print intake form for someone with a vision limitation.

Consider how this data gap creates a dangerous information void that affects disabled people's access to equitable care. A disabled patient whose preventive diagnostic exam is delayed for months because of inaccessible equipment begins to experience symptoms of a preventable condition; the condition would have been treatable if caught at an effective earlier exam. Thus, the patient's poor health status becomes correlated with disability, even though her poor health was the direct result of diagnostic failures arising out of the provider's failure to recognize and plan for needed accommodations. This outcome further harms disabled people when it reinforces the perception that disability naturally and inevitably leads to poor health outcomes.

Identify Health and Health Care Disparities Affecting People with Disabilities

Healthy People 2030 defines a health disparity as, "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage." [40] People who are more likely to face societal exclusion and discrimination are also at increased risk of encountering obstacles and barriers to health care, including people with cognitive, sensory, physical, or other disability.[41] Even so, this population has been largely overlooked in clinical and administrative health data collection and analyses.[42]

Recent population research has shown that disabled people experience significant health and health care differences when compared with people who do not have disabilities. Disability affects how individuals interact with social institutions such as schools, employers, healthcare services, housing, and community infrastructure

including transportation. Barriers to full participation at this intersection lead to less education and employment, reduced community engagement, low-income status, and poorer health for disabled people.[43] Similarly, the effects of disability can interact with other marginalized identities to compound inequities in social determinants of health (SDOH) and health disparities.[44] For instance, disabled people consistently report higher rates of chronic health conditions such as heart disease, asthma, higher weight, and diabetes than people without disability.[45] Disabled people, are twice as likely as people who do not have disabilities to skip needed care because of cost even if they have health insurance.[46] Similarly, disabled people are significantly less likely to receive preventive care even though they experience higher rates of chronic disease than the general population.[47]

Even though there is growing evidence describing these differences, health care and public health organizations have been slow to accept that they might stem from inequities rather than from disability.[48]

If disability data was readily available from the patient record, health care providers, plans, and programs could develop a clearer understanding of the health status of disabled patients and the ways in which they could participate in preventive care and treatment. The data could reveal the SDOH that affect patients' access to care and target needed clinical and non-clinical assistance such as medication management, nutrition support, home and community-based services, home modifications, or case management needed to coordinate services and supports. Moreover, when disability functional limitation information can be easily accessed in the EHR, health care providers likely would begin to see accommodations as an element of best practices that can be planned rather than an unexpected imposition. The result should be a reduction in poor health outcomes arising from inaccessibility.[49]

Lack of disability data in the EHR and administrative record also inhibits research and population health study. Without functional limitation data, health care organizations, health plans, and state health agencies engaged in population health management cannot determine accurately which disabled members could benefit most from services such as enhanced case management, transportation support, or programs intended to mitigate unequal access to medical care during public health emergencies such as COVID-19.[50] Such data would enable researchers to identify certain SDOH that affect health equity, such as concerns about cost of care, poor access to transportation, or ineffective provider-patient communication because ASL

interpreters or extended exam time are not available. The data could also be used to compare the health of disabled and non-disabled patients and explore with more accuracy how inequities manifest among other marginalized demographic groups when disability is also present. Further, researchers could evaluate health care quality, identify patterns of unequal care affecting disabled people, or analyze how disparities arise or are exacerbated when people live at the intersection of multiple demographic identities including disability, race, ethnicity, age, gender identity, and sexual orientation. As a result of not having this data, the ubiquitous lack of needed accommodations for disabled individuals is not included in burgeoning national, state, and local efforts to develop and apply health equity and quality measures.

The National Institutes of Health (NIH) has taken or proposed steps in 2023 that acknowledge a growing body of research establishing that people with disabilities experience health disparities. In late September 2023, the National Institute on Minority Health and Health Disparities (NIMHD) at NIH, designated people with disabilities as a health disparity population.[51] This enables NIH funding to flow toward projects that have a focus on health disparities experienced by disabled people and allows for the targeted recruitment of people with disabilities as both researchers and clinical research subjects. A new Notice of Funding Opportunity (NOFA) for research that addresses how disability, race and ethnicity, and socioeconomic status intersect to affect the health and healthcare of persons with developmental and physical disabilities was announced at the same time. In August 2023, the NIH opened a Request for Information that sought public comment on a proposed change in part of the NIH mission statement:

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

> Proposed: "To seek fundamental knowledge about the nature and behavior of living systems and **to apply** that knowledge **to optimize health and prevent or reduce illness for all people**."[52]

Both steps encountered resistance within NIH. An NIH Advisory Committee had initially recommended against recognizing people with disabilities as a health disparity population despite research to the contrary stretching over decades. The disparities designation was only awarded after NIH received two letters protesting the

recommendation, one signed by 1,291 health care providers, researchers, people with disabilities, and care providers, and the other by 175 advocacy organizations. As multiple levels of government and health care entities commit to gathering demographic disability information, our capacity to demonstrate the existence of disability-related health and health care barriers will grow, along with our capacity to develop systemic ways to minimize those barriers across peoples of different races, ethnicities, ages, sexual orientations, and gender identities.

Deepening Understanding of Intersectional Disparities

Although disability is present across all segments of society, prevalence is higher among some racial and ethnic groups than others. For instance, 41 percent of American Indians and Alaskan Natives have disability.[53] Twenty-nine percent of Black adults and 34 percent of multiracial adults experience disability while 29 percent of Hispanic adults report disability.[54] In comparison, about 24 percent of non-Hispanic white adults have a disability.[55]

People with LGBTQI+ identities are also more likely to have disability. A 2023 survey by the Movement Advancement Project and the Center for American Progress found that nearly one in four Lesbian, Gay, Bisexual, or Queer people has a disability, and about two in five Transgender people have a disability.[56]

Members of these groups experience racism, transphobia, and other forms of marginalization in addition to historic forms of disability bias and discrimination in ways that are both separate and compounding.[57] For instance, some studies have explored intersectional disparities among women with disabilities, including racial and ethnic differences in screening for rates of breast and cervical cancer. One study reported that 51 percent of Black women with intellectual and developmental disabilities had received a mammogram during a two-year period compared with 76 percent of white women with the same disability.[58] Similar disparities were found in a study of Deaf women.[59] Chronic health conditions and risk factors also are unevenly distributed among members of racial or ethnic groups who also experience disability. For example, 14 percent of non-Hispanic white adults with disabilities have diabetes compared with between 20 and 21 percent for Black, Hispanics, and other multiracial adults. [60]

Disabled people who identify as LGBTQI+ also report higher instances of fair or poor health compared with those disabled people who identified as non-LGBTQI+.[61] In one survey of more than 26,000 transgender people, 39 percent reported having a disability. One in three lesbians and one in three bisexual women report having a disability in a population-based survey.[62] Relatedly, those who identified as disabled and LGBTQI+ are more likely to report encountering a health care provider who had refused to provide care, being unable to afford or access care, and having to teach their provider about how to provide clinically and culturally appropriate care.[63]

These variations strongly suggest that health problems are not inevitable or unavoidable among disabled people, but rather represent the effects of bias, discrimination, and disparities in income, education, and access to health care and other SDOH.

Disability data could help programs, plans, providers, researchers, and advocates understand how the experience of engaging with health care systems and health outcomes differ when people with one or more marginalized identities also have disability. Moreover, this data will help researchers and practitioners parse the complex role bias, discrimination, and inequities play in health and health care disparities. On the individual patient level, the data will improve care for disabled people who need access to accommodations as well as culturally competent, clinically appropriate care.

The Current State of Disability Data Collection in Healthcare

Advocates have long been calling for self-identified demographic disability data to be included in electronic health and administrative records, but the COVID-19 pandemic highlighted in stark terms how this data could save lives. Without this data, public health researchers could not accurately evaluate the impact of the COVID-19 pandemic on disabled individuals living in the community and in institutional settings. Lack of data obscured the experiences of disabled individuals with other marginalized identities and stymied public health officials' ability to plan for future public health emergencies. Equally important, disabled individuals who need accommodations and policy modifications for effective healthcare were afraid that the absence of this

information from electronic health records left them vulnerable to substandard care and stereotyped assumptions about their capacity to respond to medical treatment should they contract COVID-19.[64]

This information vacuum, along with increasingly recognized health and health care inequities and disparities disabled people experience, elevated awareness about the need for disability data. As a result, several federal agencies and some states have acknowledged the data gaps, and university medical centers have initiated programs to test methods for collecting disability data among patient populations. While these efforts are still fragmented, they indicate an encouraging trend and provide a foundation for future action.

Federal Agency Action

The National Council on Disability (NCD)

NCD is an independent federal agency that advises the President, Congress, and other governmental agencies regarding policies, programs, practices, and procedures affecting disabled people. For many years, NCD has actively raised concerns about health inequities and disparities disabled people experience. In February 2022, NCD released a "Framework to End Health Disparities of People with Disabilities." The Framework calls explicitly for "Improving data collection concerning healthcare for people with disabilities across the lifespan." [65] In the agency's year one update on progress reaching the Framework's goals, published in 2023, NCD reported the following federal agency actions on improving data collection:

The Office of the National Coordinator for Health Information Technology (ONC/HIT)

In July 2022, ONC/HIT took the first steps required to include standards for documenting disability status in patient EHRs. This change will add fields for disability and functional status to the minimum nationwide interoperability standards for health information exchange—meaning that fields for disability and functional status inputs will appear on most large EHR systems by default.

These draft standards still have further to go to improve the usefulness and functionality of demographic disability data in the EHR. The standards are formatted to be placed within the disability data element under the category of health status

rather than with other demographic categories, including race, ethnicity, gender identity, and sexual orientation.[66] By electing to place the disability data element under the health status class rather than with other demographic information categories, ONC/HIT has perpetuated the conflation of disability and health status and made it more difficult for providers, office staff, and researchers to identify demographic disability data that is relevant for discerning accommodations needs and meeting research purposes. Moreover, the proposed standards also do not provide a mechanism that links specific accommodations to an identified functional limitation.[67] Nevertheless, advocates applaud this critical first step and are cautiously hopeful that the proposed standards will be moved to the patient demographic data class and after that move swiftly through the approval process toward eventually being included among mandatory provider requirements.

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Interagency Committee on Disability Research (ICDR)

Recognizing the urgent need to improve disability data collection, NIDILRR and ICDR established a working group focused on improving coordination and collaboration of disability statistics. In February 2023, NIDILRR organized a "State of the Science" conference devoted to data. The agency also provided financial support for peer-reviewed articles on improving disability data collection in health care for a special issue on health and disability for the journal *Health Affairs*, published in October 2022. For the first time, NIDILRR funded a five-year research grant on health and functioning for disabled people.

The Centers for Medicare and Medicaid Services (CMS) Office of Minority Health

In 2022, the CMS Office of Minority Health released the "Framework for Health Equity 2022-2032." The Framework sets out CMS's intent to incorporate health equity across all its programs. CMS defines 'health equity' as "…the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes." Among the Framework's five health equity priority areas, Priority 1 calls explicitly for expanding collection, reporting and analysis

of standardized demographic and language data, including disability data, across health systems. The Framework notes that this data is necessary to facilitate data alignment across federal agencies, respond to population changes over time, connect people to appropriate supports, such as home and community-based services, and work toward quality improvement. [68]

Centers for Disease Control (CDC) Inclusion of Functional Disability Measures in PLACES (Population Level Analysis and Community Estimates)

PLACES is a tool developed by the CDC that "provides model-based, population-level analysis and community estimates of health measures to all counties, places (incorporated and census designated places), census tracts, and ZIP Code Tabulation Areas (ZCTAs) across the United States.[69] In July 2023, the updated PLACES release added seven new disability measures: the six functional disability questions from the American Community Survey and a general measure on any disability. Measures from the 2021 and 2020 federal Behavioral Risk Factor Surveillance System (BRFSS) survey were also added. This means that it should be possible to use PLACES to run local queries that include information concerning the disparities and health of populations of people with particular disabilities. For example, PLACES could enable one to get a snapshot of the prevalence of people with a self-care disability in a specific geographic area who received preventive services such as a mammogram. This is the first time that local level estimates of population health have included local level disability estimates. National data on chronic conditions, behavioral risk factors, and health outcomes also continue to be available. Taken altogether, the tool should now enable local public health departments to identify health risks experienced by people with disabilities, including those living in rural areas, in the context of national and local policies and programs and determine gaps affecting people with disabilities.

State Action

Several states, including Washington and Oregon, have launched demographic disability data collection initiatives involving healthcare providers.

Oregon

Oregon enacted legislation in 2013 (HB 2134) requiring the Oregon Department of Health Services (ODHS) and the Oregon Health Authority (OHA) to develop and implement data collection standards for race, ethnicity, language, and disability, as well as sexual orientation and gender identity (REALD/SOGI).[70] Standards were codified in 2014 and updated in 2020 in response to the COVID-19 pandemic. REALD phased in data collection over several years, and all Oregon health care providers were required to collect and report REALD data to the state beginning on January 1, 2022. REALD data is being used to reveal the diversity of Oregon residents and help the state, public health officials, and researchers understand who is most affected by health and health care inequities. It also supports the value of services, community resources, and policy interventions that reduce disparities so community members can maintain good health.[71]

REALD implements a set of disability data collection questions that goes beyond the six disability questions in the American Community Survey or the Washington Group Short Set. It includes nine self-identified disability questions. The data collection tool asks all ages to voluntarily identify if they have serious difficulty hearing, seeing, or both. It asks people ages five and older about serious difficulty with mobility, cognitive processes, learning, communicating, and self-care. Those over age 15 also report problems or difficulty with independent living and mental health.[72] Regulations implementing Oregon's demographic disability data collection standards set forth the following questions for demographic disability data.

Oregon Demographic Disability Data Collection Standards

(1) A requestor must ask the following questions regarding functional limitations of individuals of any age, except as specified in section (6) of this rule:
 (a) "Are you deaf or do you have serious difficulty hearing?"
 (b) "Are you blind or do you have serious difficulty seeing, even when wearing glasses?"
(2) A requestor must ask the following questions for individuals five years of age or older:
  (a) "Do you have serious difficulty walking or climbing stairs?"

> (b) "Because of a physical, mental, or emotional condition, do you have
> serious difficulty concentrating, remembering, or making decisions?"
> (c) "Do you have difficulty dressing or bathing?"
> (d) "Do you have serious difficulty learning how to do things most people
> your age can learn?"
> (e) "Using your usual (customary) language, do you have serious difficulty
> communicating, (for example understanding or being understood by
> others)?"
> (3) A requestor must ask the following questions regarding functional limitations for
> individuals 15 years of age or older:
> (a) "Because of a physical, mental, or emotional condition, do you have
> difficulty doing errands alone such as visiting a doctor's office or shopping?"
> (b) "Do you have serious difficulty with the following: mood, intense feelings,
> controlling your behavior, or experiencing delusions or hallucinations?"
> (4) A requestor must ask the individual the following for any "yes" response to any
> question in sections (1) through (3) of this rule: "If yes, at what age did this condition
> begin?"
> (5) A requestor must ask the individual for their current age or date of birth if the
> individual answered "yes" to any one of the questions in sections (1) through (3) of
> this rule.
> (6) If a requestor is directly asking a child the questions in this rule and not a parent
> or guardian, the requestor is not required to ask a child under the age of 11 or in a
> grade level below 5th grade to answer the questions in section (1) and (2) of this
> rule.[73]

The Oregon Health Authority used preliminary REALD data from health care providers working in a health system or a federally qualified health center to understand the impact of the pandemic on marginalized communities including communities of color, refugee and immigrant communities, and people with disabilities. The report demonstrated the diversity of people living in Oregon who had experienced a case of COVID-19 or a COVID-19 health care encounter. The report found that disability status information was not available for 65.2 percent of COVID-19 cases. Authors noted that low disability reporting could be attributed to a variety of causes and called for a better understand of barriers to data collection, especially in a pandemic situation, and methods to reduce them.[74]

Washington

In June 2022, the State of Washington enacted legislation requiring that certain acute care and behavioral health hospitals report patient-identified race, ethnicity, gender identity, sexual orientation, preferred language, and disability beginning January 1, 2023.[75] Hospitals report patient demographic data to the Washington State Department of Health (DOH) through the Comprehensive Hospital Abstract Reporting System (CHARS). The DOH then sends the information to the national Centers for Disease Control and Prevention (CDC).

Covered hospitals must follow detailed reporting requirements set out by the state legislature.[76] The voluntary disability demographic questions are like the standardized questions found in the American Community Survey, however the age when people are asked to respond to the questions is not specified. The wording of the questions also varies, and the questions include an additional category involving respondent's use of adaptive equipment, such as a wheelchair or adaptive telephone.[77] The demographic disability data collection rules also include 12 options for reporting patient experience regarding activities of daily living and 13 options for reporting self-identified disabilities or conditions."[78]

State and federal healthcare agencies, public health officials, and researchers can use the patient demographic disability data to estimate the prevalence of disability among the hospital's patient population, and identify unmet needs, barriers, and inequalities. The data will help them identify health and health care disparities among the hospital's disabled patients and analyze the impact of these disparities on health status, health outcomes, future health, and longevity. Covered hospitals and other practitioners who have access to the same patient EHRs also can refer to individual demographic disability data as a starting point to identify patient accommodation needs.

Health care practitioners and facilities frequently and incorrectly use medical diagnosis as a proxy for functional limitation. By adding demographic disability data collection, these states have enabled providers, facilities, health plans, and public health agencies to measure health status, access, and quality more appropriately and effectively for people with disabilities. Moreover, these states also recognized that the ACS questions and the Washington Group short question set are insufficient to capture many types

and degrees of functional limitations and therefore are likely inadequate to identify and meet patient accommodation needs in clinical settings. The Washington and Oregon disability data collection requirements are significant advances.

Provider and Academic Initiatives

Researchers and health care practitioners with several university-based medical centers have initiated innovative research projects on the need for demographic disability data collection. Some of them have launched pilot programs that have tested various questions, sought feedback from disabled patients on their reaction to the questions, and embedded questions in some administrative forms and medical record locations within their health care services centers. These centers have developed and tested practical and effective methods to collect disability data and made significant advances in implementing their use.

The Disability Equity Collaborative (DEC)

In 2018, researchers at the University of Colorado Anschutz created DEC to address the significant issues of unequal access to healthcare for people with disabilities. In 2019, an Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) enabled DEC to be formally established. DEC supports a national collaboration of disability accessibility coordinators within health care organizations. DEC leaders also have assembled a wide variety of resources that support health care equity initiatives and identified research needed to improve accessibility and quality of health care for disabled people.

Since its inception, DEC leaders have been concerned that healthcare organizations and practitioners do not routinely collect demographic disability data in patient EHRs. They have conducted strategic research and built alliances with EHR software developers in a multi-pronged effort to garner support for collecting disability data. Researchers associated with DEC undertook a pilot study to evaluate outcomes when call center staff at the Colorado academic hospital system requested disability status information from new primary care patients registered for a clinical visit. Call center staff received training on how to document disability status, and the pilot study took place over six-weeks. One of the 53 primary care clinics registered 3,673 new patients during the study period. Completed disability status questions in the EHR increased from 9.5 percent at baseline to 53.5 percent by the last week of the trial. The pilot

revealed that no patients reported being unwilling to answer the questions, however, it revealed some inconsistencies in how and if call center staff asked the questions. This study served as a 'proof-of concept.' That is, demographic disability data could be collected successfully for disabled patients when they schedule a clinical visit with a health care provider.[79]

DEC leaders also brought the EHR software developer Epic, used by 32.9 percent of acute care hospitals, into early conversations about the lack of demographic disability data fields in the company's products.[80] Following several years of participation in DEC workgroups, in December 2022 Epic released a structure within its software for disability status data. At this point, the structure basically comprises a lengthy list of possible functional limitation elements (e.g., "autism spectrum disorder," or "Deaf/does NOT use sign language," or "manual dexterity disability) that generally correspond to one of the six ACS disability questions or the communication question from the Washington Group Short Set. The list does not come in a question format and providers ask about possible functional limitations however they wish to obtain a "yes/no" answer. However, EPIC could well decide to work on including a set of written-out disability questions in patient-facing forums such as e-check-ins and patient portals; providers would prefer this option as it demands less "extra work" from staff. A uniform set of disability questions would also be more likely to solicit more consistent and reliable demographic data. All providers who use Epic should have the data element structure available to them in 2024 or 2025. It may take longer for the disability structure to be a "forced" update that will become automatically embedded in the EHR software for all users whenever they next update their Epic software, which typically takes place every six months.

DEC will continue to work on building data collection tools, that is, refining how the disability data fields will appear to providers, supporting providers in obtaining accurate answers, and considering ways to maximize the functionality of the disability status fields by connecting them to other applications within the EHR. With support from the National Institutes of Health (NIH), DEC is evaluating tools by piloting the disability questions and various queries about accommodation needs at the University of Colorado Medical Center. DAC leaders are hopeful that Epic will accept the outcomes of the pilot and release a standardized version of the disability questions that all clients will receive automatically. DAC leaders also recognize that most health care organizations work through a vendor or contractor to transition to, modify, or

upgrade Epic. These contractors will require education about the importance and availability of the disability element and related questions, and the various locations where clients can access them in the EHR.

DEC also created a toolkit that health care organizations can use to document disability status and identify required accommodations in whatever EHR software they use. The toolkit is presented in a Question-and-Answer format and includes appendices with additional resources.[81]

The University of Michigan Medical School

Michigan Medicine, the health system owned by the University of Michigan Medical School, created the Disability and Accommodations Tab (referred to as the "Disability Tab"), a shared data field based on a questionnaire located in Michigan Medicine's version of Epic, the EHR software. Patients can record accommodations they require through the patient online portal, called MiChart. Medical personnel can also complete the questionnaire through the care team side of the portal. Patients can complete the optional questionnaire in the same location where those for gender identity and sexual orientation questionnaires can be found. Michigan Medicine works in consultation with its Disability Resource Group, people with disabilities, disability advocacy groups, and clinical staff who routinely work with people with disabilities.

The Disability Tab offers measures of disability that differ from the Washington Group Short Set (WGSS) and the six American Community Survey (ACS-6) questions. In selecting disability demographic categories, the developers recognized that functional differences are present within a single disability category, thus sometimes obscuring possible accommodations needed in response to the varying levels of functionality. For instance, someone who indicates they have a vision impairment might have some limited vision and therefore requires large print materials while another person might experience total blindness and require information in Braille or a digital format. Or someone who indicates that they have difficulty concentrating or remembering could indicate that they benefit from a separate quiet place to wait for their appointment or that they need to have morning appointments because that is when their mental focus is sharpest given how their medication cycle works. Michigan Medicine also recognized that specific disabilities related to communication and mental health were not well represented in the WGSS or ACS-6 disability questions. Instead, the Disability Tab asks, "What type of disability(s) do you have?" Respondents can choose among

blind/low vision; cognitive, intellectual, or developmental; hard-of-hearing, deaf, deaf-blind; mental health; mobility disability and wheelchair use; respiratory; speech/communication; other sensory; upper body and fine motor skill impairment; or none. Once a type of disability(s) question is answered, the questionnaire asks about accommodation needs for each identified disability. For instance, individuals who indicated they are hard of hearing, deaf, or deaf-blind can choose among 10 communication assistance options, including assistive listening devices, ASL interpreter, and real-time captioning.

The Disability Tab went live in the patient portal in October 2020. Even though Michigan Medicine did not immediately incorporate this feature in clinical workflows, by September 2022, 4732 patients had filled out the questionnaire through the patient portal. Patient demographic disability data revealed that, for example, 24 percent of patients had mobility disabilities or used wheelchairs. More than 16 percent were hard of hearing, deaf, or deaf-blind, and 13.8 percent reported cognitive disabilities. Developers of the Disability Tab recognized that disabilities could change over time and accommodation needs can also change. They created a "button" (timestamp) in the electronic record that identifies the last person who used or reviewed the Tab to help track the currency of the information in the questionnaire. Michigan Medicine leaders who championed the Disability Tab recognize that work remains to integrate the identified accommodation fully into clinical workflows; they also recognize that barriers arising from Limited-English Proficiency or limited internet access may prevent patients from using the online questionnaire. The primary purpose of the Disability Tab is to collect information that will help clinical staff provide effective accommodations for patients rather than for demographic data collection and analysis. [82] The following chart shows some of the differences between parallel measures in the ACS-6, WGSS, and Michigan Medicine approaches.

Question Focus on Patient Accommodation Needs Rather than Demographic Disability Information

Question Source	Question Text	Follow-up Accommodation Request
American Community Survey[83]	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	N/A
Washington Group Short Set	Do you have difficulty remembering or concentrating? Would you say… 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	N/A
Michigan Medical[84]	What type of disability(s) do you have? "Cognitive, Intellectual, or Developmental" (one of 10 choices, including "none")	• Assistance with completing surveys/patient intake • Check for understanding • Closed captioning during video visits • I want to give people information in advance, before going to the clinic (see 'other') • I have a support person, please involve them in my medical discussions • Provide directions/follow-up in writing • Use visuals or pictures to explain concepts • Modifications to the COVID-19 mask policy • Modifications to the COVID-19 visitor policy • Need for reduced sensory input • Other, please specify

What Needs to Change in Health Data Collection

The Limitations of Current Data Collection Methods

Notwithstanding recent advancements described above, most health care organizations primarily collect and report administrative claims data that relies on diagnostic or procedural codes. Although important for quality patient care, these data do not capture the fundamental distinction between diagnosis and self-identified functional limitation, a defining element of accurate demographic disability identification. (Refer to Part II for a detailed discussion of why diagnostic information is insufficient to measure disability as a demographic).

The limitations of this approach are reflected in the experience of people with many different disabilities during the COVID-19 pandemic. The failure to demographically identify people with disabilities left advocates unable to pinpoint how COVID-19 affected the population of people with disabilities at large as well as smaller subgroups of people with certain disabilities. For instance, it was virtually impossible to identify how many disabled people living in the community and outside of institutions were infected, hospitalized, and died from COVID-19. Data were not available that illustrated how a specific functional limitation, such as lack of mobility or blindness, affected the person's opportunity to book a vaccination appointment or receive vaccinations, particularly when facilities or means of making an appointment were inaccessible. The elevated risks that disabled people faced from the virus when they needed personal care assistance in their homes couldn't be measured, especially when direct care workers were unable to work for various pandemic-related reasons and when personal protective equipment was both expensive and unavailable. The lack of functional limitation information in EHRs for people with vison, speech, communication, intellectual, and other disabilities affected how emergency department providers would rank them for emergency care using medical predictive mortality tests in widespread use, such as the Glasgow Coma Score. Providers sometimes made life and death decisions based on incorrect assumptions and stereotypes about people with specific disabilities. Disabled people were left terrified of winding up in an emergency department and unable to fully indicate their

functional capacity or needs, or likelihood of responding to treatment should care be triaged during a surge situation.[85]

Recommendations for Including Demographic Disability Data

The following recommendations are at a high level so that they can be undertaken in some form by a range of entities, from state governments, state public health departments or single Medicaid agencies, to national entities that work on health care equity and quality measures, and even local public health authorities. Leadership and standard setting should come from the federal government to enable disability data, particularly for very small subpopulation groups of individuals with disabilities who hold other personal characteristics, to be collated across states, regions, or multiple time periods to maximize statistical significance while preserving needed deidentification.

Demographic disability data must be undertaken at every step with input and leadership from diverse groups of people with disabilities.

1. The collection of demographic disability data must be undertaken at every step with input and leadership from diverse groups of people with disabilities and disability advocates whose wellbeing rests on the collection of this information, and who are best situated to communicate the importance of demographic disability information for health care equity and equality. For example, a health plan could establish a stakeholder advisory committee that brings together people with disabilities and disability advocates who have experience across a range of health care coverage and delivery systems, data experts, and policy makers to establish goals, a timeline, and an assessment and feedback process for collecting disability data.

2. Consider how the three uses of demographic disability data (patient accommodations, disparities research, intersectional research) can best be accomplished through:

   a. The set of disability questions chosen,[86]

b. The specific mediums used to gather data (e.g., census, federal or state surveys, electronic health records),[87]

c. The entities that will be responsible for collecting, storing, using, and potentially sharing the information with other health care partners,

d. The current and potential data and privacy protections that apply to different entities that will have access to demographic disability information,

e. A commitment to making questions mandatory to be asked but voluntary to answer through self-disclosure.

3. Build on a strong existing base of research on how to measure disability which has been created both within the United States by such agencies as the Census Bureau (*i.e.*, the ACS-6) and internationally by the United Nations.

4. Maintain a "feedback loop" that will allow disability questions to continue to be refined in ways that will allow for the inclusive capture of people with different disabilities, as well as people with disabilities who come from different racial and ethnic cultural backgrounds or who have limited English proficiency.

5. Prioritize the importance of educating the public, health care entities, and people with disabilities and their families on the importance of demographic data collection to health care equity and effectiveness for people with disabilities.

6. Establish standards for how demographic disability information will be collected by a range of health care entities and appoint an agency or division at the relevant county, state, or federal level that will be responsible for providing technical assistance, monitoring, and enforcing the standards across entities responsible for data collection.

7. Build in assessment processes from beginning to end that will enable tracking of the effectiveness of outreach and education on completeness of demographic disability data, whether response rates are improving over time, and how to achieve granular information on whether people of color,

immigrant populations, and LGBTQ+ individuals are comfortable with and answering disability questions.

8. The federal government must coordinate with states and other health care equity bodies to create an overarching coordinating initiative that will provide guidance and best practices for state and local entities to include demographic disability data collection to all the health care surveillance efforts undertaken in the country, and particularly efforts that are aimed at improving health care quality, embedding equity and inclusiveness within health care delivery, and placing guardrails around the gathering of Big Data and the use of automated health care decision-making tools and systems. [88]

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[22] *Id*.

[23] M. A, Morris, M. K. Hamer, K. Eberle, et al., *Implementation of Collection of Patients' Disability Status by Centralized Scheduling*, 47 JOINT COMM'N J. QUALITY & PATIENT SAFETY 627-36 (2021), https://doi.org/10.1016/j.jcjq.2021.05.007.

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Off. Mgm't & Budget, Proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising OMB's 1997 Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15), 88 Fed. Reg. 5375, 5375-84 (Jan. 27, 2023), https://www.federalregister.gov/documents/2023/01/27/2023-01635/initial-proposals-for-updating-ombs-race-and-ethnicity-statistical-standards.

[25] The U.S. Census Bureau has been engaged for some years in reviewing the disability data elements used in the census and federal surveys and proposes a change from the ACS-6 to a question set that uses the levels of disability found in the WSGG and adds a question. Many disability researchers and advocates believe the change could result in even more significant undercounts of people with disabilities and lead to reduced resources to meet the needs of people with disabilities in the United States. *See* 88 Fed. Reg. 72424 (October 20, 2023), https://www.federalregister.gov/documents/2023/10/20/2023-23249/agency-information-collection-activities-submission-to-the-office-of-management-and-budget-omb-for.

[26] A number of states administer a core federal set of survey questions, augmented by state-chosen additional question sets. *See* for example Dep't Health & Hum. Servs., *Behavioral Risk Factor Surveillance System (BRFSS)* https://health.gov/healthypeople/objectives-and-data/data-sources-and-methods/data-sources/behavioral-risk-factor-surveillance-system-brfss (last visited Nov. 9, 2023).

[27] Based on Section 4302 of the Affordable Care Act, the U.S. Department of Health and Human Services issued data collection standard guidance to include a standard set of disability identifiers in all national population health surveys. Dep't Health & Hum. Servs., Ofc.

Assistant Sec'y Planning & Evaluation, *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status* (Oct. 30, 2011), https://aspe.hhs.gov/datacncl/standards/aca/4302/index.pdfpdf icon.

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[35] J. P. Hall et al., *Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy*, 41 HEALTH AFFS.1433-1441 (2022), https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00395.

[36] *Id*.

[37] Rehabilitation Act of 1973 § 504, 29 U.S.C. §794; Nondiscrimination on the Basis of Handicap in Programs or Activities Receiving Federal Financial Assistance, 45 C.F.R. Part 84.

[38] Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq.

[39] Patient Protection and Affordable Care Act § 1557, 42 U.S.C. § 18116 et seq.

[40] Healthy People 2030, *Health Equity in Healthy People 2030*, https://health.gov/healthypeople/priority-areas/health-equity-healthy-people-2030 (last visited Nov. 14, 2023).

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[43] W. Horner-Johnson, *supra* note 10, G. L. Krahn et. al., *supra* note 9.

[44] S. Yee, M. L. Breslin, T. Goode, et. al., *supra* note 13.

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[46] W. Horner-Johnson, *supra* note 10.

[47] M. Mitra, L. Long-Bellil, I. Moura, et al., *supra* note 30.

[48] W. Horner-Johnson, *supra* note 10.

[49] G. L. Krahn et. al., *supra* note 9; W. Horner-Johnson, *supra* note 10.

[50] I. Akobirshoev et al., *Delayed Medical Care And Unmet Care Needs Due To The COVID-19 Pandemic Among Adults With Disabilities In the US*, 41 HEALTH AFFS. 1505 (2022), https://www.healthaffairs.org/doi/epdf/10.1377/hlthaff.2022.00509.

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[60] Ctrs. Disease Control & Prevention, *supra* note 34.

[61] W. Horner-Johnson, *supra* note 10.

[62] Movement Advancement Project, *supra* note 56; W. Horner-Johnson, *supra* note 10.

[63] C. Medina & L. Mahowald, *supra* note 8.

[64] E.M. Lund & K.B. Ayers, *Ever-Changing But Always Constant: "Waves" of Disability Discrimination During the COVID-19 Pandemic in the United States*, 15 DISABILITY HEALTH J. (Oct. 2022), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9436863/.

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[74] Oregon Health Auth., *COVID-19 REALD Report* (Feb. 19, 2021). https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le1128136.pdf. Slightly less than four percent of reported COVID-19 cases and 7.2 percent of COVID-19 encounters were among individuals who identified having a disability. Healthcare providers reported disability acquired either before the age of 19 or at age 50+ among people who had experienced more COVID-19 encounters than cases might reflect coordinated testing efforts in congregate living settings.

[75] Ashlen Strong, Wash. State Hosp. Ass'n, *Beginning January 1, 2023 – New Rules for Hospital Patient Discharge Information Reporting (2021 Session E2SHB 1272)* (Aug. 23, 2022), https://www.wsha.org/articles/beginning-january-1-2023-new-rules-for-hospital-patient-discharge-information-reporting-2021-session-e2shb-

1272/#:~:text=Beginning%20January%201%2C%202023%2C%20hospitals,CHARS%20according%20to%20detailed%20specifications.
A waiver process is available for critical access hospitals, sole community hospitals, and hospitals that qualify as a Medicare dependent hospital. Eligible hospitals may apply for a waiver due to economic hardship, technological limitations that are not reasonably in the control of the hospital or other exceptional circumstances as attested to by the hospital. Hospitals that are granted a waiver are exempt from reporting the additional patient discharge information for a period of one calendar year, beginning on the calendar month following waiver approval.

[76] Wash. Admin. Code § 246-455-025 (2023), https://app.leg.wa.gov/WAC/default.aspx?cite=246-455-025.

[77] *Id*.

[78] Ashlen Strong, *supra* note 75. One of the authors of this brief had a personal conversation in October 2023 with an individual from the Washington State Department of Health who indicated that the roll-out of the new data collection rules at hospitals had been challenging to date, but the process is still in only the first year of implementation. The state's learning curve and data insights as the process continues will provide valuable guidance to other states that are considering implementing disability data collection measures.

[79] M. A, Morris, M. K. Hamer, K. Eberle, et al., *supra* note 23.

[80] Kat Jercich, *Epic Still Leads EHR Choices Among Large Orgs, says KLAS*, HEALTHCARE IT NEWS, Apr. 26, 2022, https://www.healthcareitnews.com/news/epic-still-leads-ehr-choices-among-large-orgs-says-klas.

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[82] H. Halkides, T. James, M. McKee, et al., *Spotlighting Disability in a Major Electronic Health Record: Michigan Medicine's Disability and Accommodations Tab*, 6 JMIR FORM RES. (2022), https://formative.jmir.org/2022/12/e38003.

[83] Washington Group on Disability Statistics, *WG Short Set on Functioning*, https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/ (last visited November 29, 2023).

[84] H. Halkides, T. James, M. McKee, et al., *supra* note 82.

[85] Nat'l Council Disability, *2021 Progress Report: The Impact of COVID-19 on People with Disabilities* (2021), https://ncd.gov/progressreport/2021/2021-progress-report.

[86] There is a growing body of research that looks at the effectiveness and accuracy of different sets of disability questions for capturing the prevalence of people with disabilities in the general population and within population subgroups. *See*, for example, J.P. Hall et al., supra note 35.

[87] The more that U.S. healthcare entities can adopt a uniform set of disability questions, the greater the potential for comparing data, obtaining participant numbers that allow for statistical significance in analysis, and providing needed accommodations to individuals with

disabilities even if they change residences and healthcare providers. Nonetheless, there is still a strong argument to be made that including a distinct in-depth and disability-specific component in the decennial census will provide policy and lawmakers with an indispensable source of information for understanding and meeting the needs of people with a range of disabilities. *See* the arguments for multiple data approaches raised by Nora Ellen Groce, University College London, Inst. Epidemiology & Health Care, *Which one to use?: The Washington Group Questions or The Model Disability Survey*, https://www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-or-model-disability-survey-0 (last visited Nov. 14, 2023).

[88] This paper does not detail the specific risks that health-related data can pose to people with disabilities, especially when demographic disability data collection remains so nascent in health care, but the subject has been examined in S. Yee & M.L. Breslin, Disability Rts. Ed. & Def. Fund & Nat'l Health L. Program, *Risks and Rewards of Demographic Data Collection: How Effective Data Privacy Can Promote Health Equity* (Mar. 2023), https://healthlaw.org/wp-content/uploads/2023/03/This-Data-Not-That-Data_Disability-Rights-Education-and-Defense-Fund_FINAL.pdf.