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Lack of disability data
impedes healthcare equity

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The missing billion: Lack of disability data impedes healthcare equity

Addressing the absence of health data on people with disabilities is the essential first step health systems and policy makers can take to reduce care inequity and improve outcomes for this population.

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Around the world, 1.3 billion people, or 16 percent of the population, are living with significant disabilities, according to the World Health Organization (WHO).[1] By and large, these individuals experience more barriers to accessing healthcare than the general population (see sidebar "Defining 'disability' and effects on care access and outcomes"). As a result, the United Nations' goal of "ensuring healthy lives and promoting well-being for all at all ages" will be very difficult to achieve.[2]

Defining 'disability' and effects on care access and outcomes

There are many types and categorizations of disabilities. According to the World Health Organization, disabilities result from the interactions between individuals with an impairment and personal and environmental factors, including negative attitudes, inaccessible transportation and public buildings, and limited social support.[1] Impairments can be physical, mental or psychosocial, intellectual, and sensory.

Additionally, people with disabilities often have greater care needs, in part because they develop health conditions due to their impairments or underlying health (for example, immobility caused by a stroke could result in bedsores). They also are more likely to belong to cohorts with greater healthcare needs. For example, people with disabilities are older, on average, than the general population[2]; therefore, they are more likely to have chronic diseases or other conditions that necessitate more care. The prevalence of disabilities is also higher in women, who face greater barriers accessing health services in some settings,[3] and the poor, who experience overall worse health as a result.[4]

On average, people with disabilities have substantially worse health outcomes, with a mortality rate twice as high as the general population's and a life expectancy that is ten to 20 years shorter.[5] This is due in part to disparities across the whole patient journey (for example, the ability to access and pay for services). In a survey conducted in five countries (Brazil, France, Japan, the United Kingdom, and the United States), people with a disability also reported greater distrust of the healthcare system than the general population (73 percent compared with 56 percent). Among ethnic minorities and people of color who are also disabled, the disparity is even higher (82 percent compared with 52 percent who are neither).[6]

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[1] "Disability," World Health Organization, accessed August 22, 2023.
[2] "Ageing and disability," UN Department of Economic and Social Affairs, accessed August 22, 2023.
[3] Lena J.P. Cardoso, Anna Gassman-Pines, and Nathan A. Boucher, "Insurance barriers, gendering, and access: Interviews with Central North Carolinian women about their health care experiences," *Permanente Journal*, 2021, Volume 25, Number 2.
[4] "Realizing the Sustainable Development Goals by, for and with persons with disabilities: Ending poverty and hunger for all persons with disabilities (Goals 1 and 2)," UN Department of Economic and Social Affairs, 2019.
[5] *Reimagining health systems that expect, accept and connect 1 billion people with disabilities*, Missing Billion Initiative and Clinton Health Access Initiative, 2022; "People with learning disabilities had higher death rate from COVID-19," UK Health Security Agency, November 12, 2020; Maarten Cuypers et al., "All-cause and cause-specific mortality among people with and without intellectual disabilities during the COVID-19 pandemic in the Netherlands: A population-based cohort study," *Lancet*, May 2023, Volume 8, Number 5.
[6] Sanofi survey on trust in healthcare system of 11,500 people in five countries (Brazil, France, Japan, the United Kingdom, and the United States); for more, see "A million conversations: How we're bridging the healthcare 'trust gap' with marginalized communities," Sanofi, April 3, 2022.

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[1] "Disability," WHO, accessed August 22, 2023.
[2] "Goal 3: Ensure healthy lives and promote well-being for all at all ages," Sustainable Development Goals, United Nations, accessed August 22, 2023.

People with disabilities have a right to add years to their lives and life to their years through better health.[3] Closing health outcome gaps between populations with and without disabilities—in all dimensions of health (physical, social, mental, and spiritual)—calls, first and foremost, for good data. However, there are sizable and persistent gaps in health data with respect to people with disabilities.[4] In a 2023 review of data sets across 188 countries, 63 had no data sets with functional-difficulty questions[5] between 2009 and 2022.[6] As described in the McKinsey Health Institute's (MHI) six shifts to reach the full potential of human health,[7] better data is needed to do the following:

+ raise awareness of the scale and nature of disparities in health outcomes; measurement is foundational to improvement

+ determine, and build awareness of, the benefits of improving health equity and outcomes for people with disabilities[8]

+ identify and quantify the healthcare access barriers experienced by people with disabilities

+ determine ways to close the health outcome gap by using data to inform and scale "what works" given that interventions often do not translate into action[9]

+ establish a baseline with standardized measurements, set targets, and monitor the progress of interventions

MHI is working with the Missing Billion Initiative to address health system challenges and close this gap in health data and equity (see sidebar "About the Missing Billion Initiative and the McKinsey Health Institute").[10] In this first report, we explore how a lack of health data exacerbates the challenges of meeting the needs of people with disabilities. We also share analysis of the maturity levels of different countries with respect to data collection and usage, and we outline actions stakeholders could take to close the health data equity gap.

About the Missing Billion Initiative and the McKinsey Health Institute

The Missing Billion is a global initiative committed to improving access to health for the 1.3 billion people around the world who have disabilities. The McKinsey Health Institute (MHI) is a non-profit-generating entity of McKinsey and includes health equity as a focus area.

The Missing Billion and MHI are working in partnership to accelerate the movement on inclusive health and develop use cases across countries. A foundational part of this effort is jointly publishing novel insights to demonstrate the health data, access, and outcome gaps for people with disabilities globally.

People with disabilities have a right to add years to their lives and life to their years through better health.

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[3] For more, see "McKinsey Health Institute," McKinsey, accessed August 22, 2023.

[4] *Adding years to life and life to years*, McKinsey Health Institute, March 29, 2022.

[5] Functional-difficulty questions assess difficulty in performing basic everyday tasks or more complex tasks needed for independent living.

[6] J. Hanass-Hancock et al., *The disability data report*, Disability Data Initiative and Fordham Research Consortium on Disability, 2023.

[7] *Adding years to life*, March 29, 2022.

[8] "Equity and Health," McKinsey Health Institute, accessed August 22, 2023.

[9] "Scale what works: The benefits of proven health interventions," McKinsey Health Institute, March 29, 2022.

[10] WHO defines health equity as "the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically, or geographically." See "Health equity," WHO, accessed August 22, 2023.

Barriers to healthcare access

People with disabilities often experience more difficulty accessing healthcare than the population at large, from perceiving a need to receiving treatment and follow-up care (Exhibit 1).[11]

This health equity gap persists in part because some healthcare professionals feel they lack the training and confidence to communicate with and serve people with disabilities. In a 2019–20 survey of 714 practicing US physicians, only about two in five said they were very confident in their ability to provide equal-quality care to patients with disabilities, and only three in five strongly agreed that they welcome disabled patients into their practices.[12]

Perceived negative attitudes from healthcare workers can have tangible adverse effects on the experience of patients with disabilities. For example, the care team for a visually impaired woman with HIV in South Africa assumed she didn't have sex or need family planning.[13] A man with a hearing impairment in Kenya sat in the waiting room until the office closed because he missed audio notifications that it was his turn to see the doctor.[14]

As a cohort, people with disabilities are sometimes seen as "less deserving" of care during a crisis. For example, in some US states, ventilator allocation protocols during the pandemic appeared to endorse the removal of these life-saving devices from "people using them for a chronic condition."[15] In the United Kingdom, some COVID-19 patients with learning disabilities (equivalent to intellectual disabilities in other countries) were automatically given "do not resuscitate" notices without consultation or consent.[16]

Finally, disabilities are more prevalent among certain groups that may be marginalized in other ways, further exacerbating barriers to accessing healthcare. The following are some examples:

+ Twenty-four percent of people with disabilities live below the national poverty line, compared with 13 percent of those without disabilities.[17] This is a cyclical relationship. For example, McKinsey research shows less than one-fifth of Americans with a disability are employed, compared with nearly two-thirds of those without a disability. And poverty is linked to higher risk of trauma, injury, and disease (Exhibit 2).[18]

+ Nineteen percent of women globally have a disability, compared with 12 percent of men.[19]

+ Globally, nearly half of people aged 60 or older have a disability.[20]

+ Refugees in displacement crises are twice as likely as local populations to have a disability.[21]

> # Perceived negative attitudes from healthcare workers can have tangible adverse effects on the experience of patients with disabilities.

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[11] *Reimagining health systems*, 2022.

[12] Lisa I. Iezzoni et al., "Physicians' perceptions of people with disability and their health care," *Health Affairs*, February 2021, Volume 40, Number 2.

[13] Phyllis Heydt and Hannah Kuper, *The Missing Billion: Access to health services for 1 billion people with disabilities*, Missing Billion, July 2019.

[14] *Reimagining health systems*, 2022.

[15] Bo Chen and Donna Marie McNamara, "Disability discrimination, medical rationing and COVID-19," *Asian Bioethics Review*, December 2020, Volume 12, Number 4.

[16] UK Care Quality Commission, December 2020; reported in Shaun Lintern, "Coronavirus: Unlawful do not resuscitate orders imposed on people with learning disabilities," *Independent*, June 13, 2020.

[17] Poverty data is an average of data from China, Georgia, Indonesia, Korea, Macau, Mongolia, and the United States. National poverty line is the minimum amount of money a person needs to fulfill basic necessities such as shelter and food. For more, see "Realizing the Sustainable Development Goals by, for and with persons with disabilities," 2019.

[18] Lena Morgon Banks and Sarah Polack, *The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle income countries*, International Centre for Evidence in Disability and London School of Hygiene & Tropical Medicine, 2014.

[19] Sophie Browne, *Issue brief: Making the SDGs count for women and girls with disabilities*, UN Women, 2017.

[20] Forty-six percent of people over 60. For more, see "Ageing and disability," accessed August 22, 2023.

[21] Refugees: 24.7 percent of Syrian refugees in Sultanbeyli, Türkiye, compared with 12.0 percent of the local population. For more, see Sarah Polack et al., "Disability among Syrian refugees living in Sultanbeyli, Istanbul: Results from a population-based survey," *PLOS One*, 2021, Volume 16, Number 11; Bekir Fatih Meral and H. Rutherford Turnbull, "Comparison of Turkish Disability Policy, the United Nations Convention on the Rights of Persons with Disabilities, and the core concepts of U.S. disability policy," *Alter*, July–September 2016, Volume 10, Number 3.

EXHIBIT 1

People with disabilities experience barriers to healthcare services at every stage of the patient journey.

I perceive a need, but I'm uncertain about symptoms and whether to seek care

"I was used to having frequent headaches due to having low vision and was so conditioned to the pain that I did not realize when to seek help. We only got to know about the tumor when it was at a later stage."

Adolescent with low vision

I decide to seek healthcare, but I'm concerned about the quality and accessibility of care I will receive

"When I go to a healthcare service for the first time, I worry they won't understand me, think I have a mental disability, and put me into a psychiatric hospital."

Older person with cerebral palsy and speech impairment

I reach the healthcare facility, but I'm unable to get accessible or affordable transport

"I kept checking the vaccination portal for slot availability in the nearby hospital, but it constantly showed full. There was no provision for people with disabilities, and it was too difficult and expensive for us to take her far away."

Father of a girl with physical impairment

I access healthcare services, but I'm unable to access the health facility

"I have kidney stones, so I need to keep using the washroom. But the toilet in the hospital was so inaccessible that I couldn't go there at all."

Woman with physical impairment

I engage with healthcare staff, but I'm not treated comprehensively or with respect by staff, or I have communication issues with staff

"The doctor couldn't understand that I was pregnant. I was given pain medication for stomachache and sent home."

Woman with hearing impairment

I receive treatment and follow-up care, but I'm confused about what to do after the visit

"I need assistance with my medication. Usually, the healthcare workers write the instructions on the package—for example, 1×3, 2×4, and so on—but I cannot read that."

Man with visual impairment

Source: Céleste Danos et al., *Reimagining health systems that expect, accept and connect 1 billion people with disabilities*, Missing Billion, September 2022

Poverty and disability mutually reinforce each other in a vicious cycle.
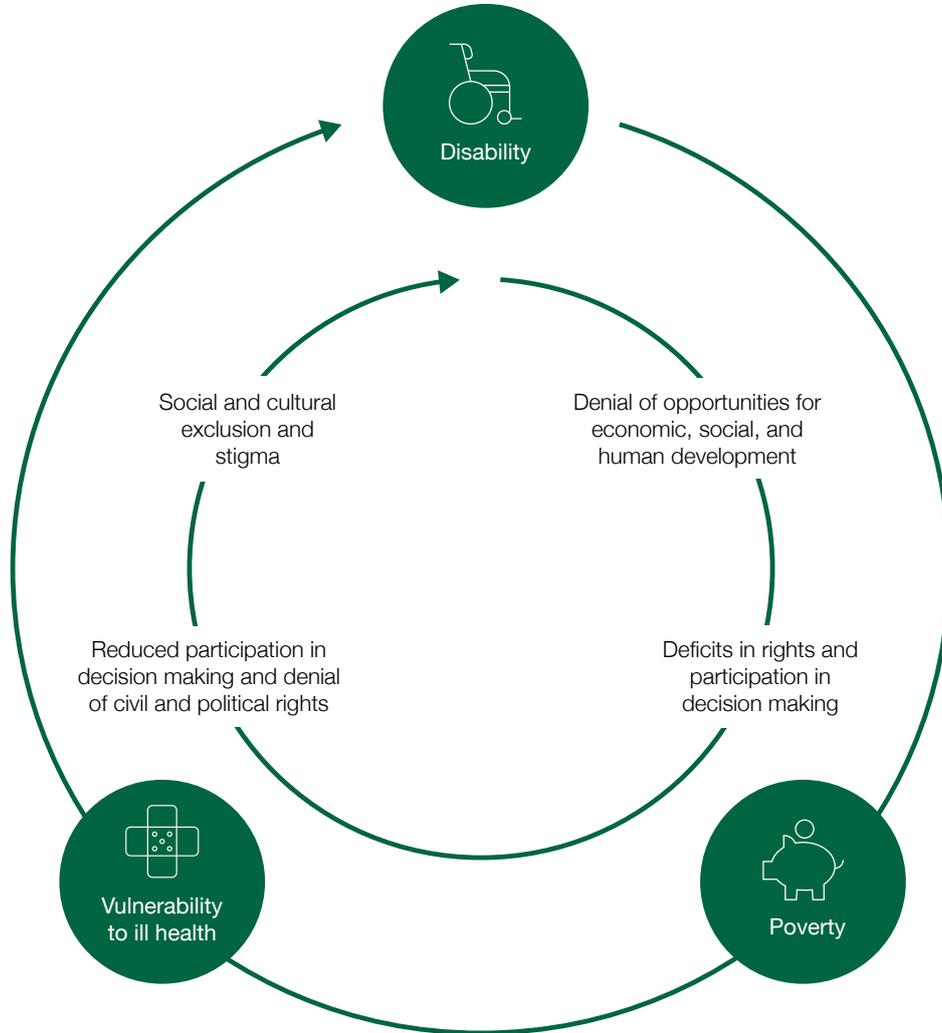
Source: Lena Morgon Banks and Sarah Polack, *The economic costs of exclusion and gains of inclusion of people with disabilities: Evidence from low and middle income countries*, CBM, International Centre for Evidence in Disability, and the London School of Hygiene & Tropical Medicine, 2014

Limitations and challenges in disability and health data

Globally, national health systems are awash in data from healthcare clinicians, pharmacies, insurers, national health questionnaires, and more. This data includes personal health data—for example, from claims, registries, electronic health records (EHRs), and testing. It also includes system-level health data (such as prescription volumes and clinical volumes) and population-level statistics (for instance, immunization coverage, mortality, and burden of disease). Much of this data can be disaggregated by age, gender, and ethnicity. This data is important because it provides insights on subsets of the population but it also gives rise to security concerns as data must be prevented from being used for discriminatory purposes.

In addition, our current understanding of the health of people with disabilities is inconsistent and limited by huge gaps in comparison data.[22] Four factors contribute to this health data inequity:

Inconsistent definitions and collection methods

There are many ways to measure disability—including self-reporting, clinical diagnosis, impairment assessment, and disability registration—but there is no standard, global definition of disability. Moreover, some conditions are difficult to measure objectively and may fluctuate over time. Making meaningful comparisons of disabled populations across countries is difficult because thresholds and criteria vary (see sidebar "Varying determinations of disability"). Increased use of questions from the Washington Group on Disability Statistics to measure disability is addressing this issue,[23] but variations in the application of this tool still lead to problems with comparability.

Data sets built using different data definitions, data formats, collection tools, and administration methods may yield quite different results. For example, the Ugandan Bureau of Statistics administered two surveys to assess the prevalence of people with disabilities—the Uganda Demographic and Health Survey (UDHS) in 2016 and the Functional Disability Survey (FDS) in 2017.[24] Both research groups used the same data collection tool,[25] but the UDHS identified an overall prevalence of disability of 8.4 percent of adults,[26] compared with 16.5 percent in the FDS.[27] This variation in results arose from differences in survey design, interviewer training processes, and targeted respondents (head of household and disabled household member), among other factors.

Lack of consistency in data methods also leads to poor data interoperability, which makes it difficult or impossible to conduct apples-to-apples comparisons across data sets, aggregate data to identify patterns and trends, and otherwise glean meaningful insights (for example, at the local and national levels).

Varying determinations of disability

A look at Vietnam and Germany illustrates the differences in how disability is determined.

Vietnam. Individuals are assessed for disability allowance by a physician based on their ability to perform eight essential activities of daily living. For each activity, they are assigned a score; the sum of those scores equates to their "disability degree," which is used to determine eligibility for benefits.

However, this method has faced criticism for its limitations in identifying individuals with psychosocial and developmental impairments. Additionally, it may underestimate the significant impact of certain conditions, such as deafness, on the ability to complete functional activities.[1]

Germany. Individuals are considered to have a disability if physical, mental, intellectual, or sensory capacities deviate for more than six months from a state that is typical for their age, resulting in prevention from equal participation in society. The degree of disability is determined by a physician on a scale from 20 to 100 in increments of ten. Anyone with a score above 50 is considered severely disabled.[2]

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1. Lena M. Banks et al., *Disability-inclusive social protection in Vietnam: A national overview with a case study from Cam Le district*, International Centre for Evidence in Disability, 2018.
2. Karsten Ingmar Paul and Alfons Hollederer, "Unemployment and job search behavior among people with disabilities during the first year of the COVID-19 pandemic in Germany," *International Journal of Environmental Research and Public Health*, June 2023, Volume 20, Number 11.

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22. *Adding years to life*, March 29, 2022.
23. The Washington Group on Disability Statistics focuses develops disability measures for use by censuses and surveys. For more, see *Disability Data Collection: A summary review of the use of the Washington Group Questions by development and humanitarian actors*, Leonard Cheshire and Humanity & Inclusion, October 2018.
24. For more about UDHS, see *Uganda demographic and health survey 2016*, Uganda Bureau of Statistics, January 2018. For more about FDS, see *Uganda functional difficulties survey 2017*, Uganda Bureau of Statistics, July 2018.
25. Washington Group Short Set Questions with the same threshold. Percentages reflect respondents ages five and up, both sexes, who reported "a lot of difficulty" or "cannot do at all" in at least one domain. For more, see "Washington Group Short Set Questions," Washington Group on Disability Statistics, accessed August 23, 2023.
26. *Uganda demographic and health survey*, January 2018.
27. *Uganda functional difficulties survey*, July 2018.

Missing data

Many countries collect no data on disabilities. For example, according to a 2021 report by the Disability Data Initiative, one in four countries included no questions about disabilities in national censuses and household surveys from 2009 through 2018.[28] And the initiative's 2023 report found that about four in five countries did not include questions about functional difficulty in national censuses and household surveys from 2009 through 2022.[29]

Additionally, most disability data sets are collected on a one-off basis (making it impossible to conduct comparisons over time), do not cover many types of disability (for example, communication impairments), and focus narrowly on disabilities caused by disease. The lack of disability data collected within routine EHRs results in another major missed opportunity to disaggregate these rich data sources by disability.

In the meantime, governments and other stakeholders benefit from nationwide disability data sets, disaggregated by impairment type, that determine healthcare access and needs and inform national healthcare plans. Moreover, healthcare professionals, policy makers, and other stakeholders lack access to large-scale, comprehensive, consistent, disability-specific data sets that could present a fuller picture (across social, economic, public health, clinical, and life-stage lenses) of the lived experiences of those with disabilities.

An additional challenge in collecting and analyzing health data is that data collectors must have core competencies in data privacy and security.[30] A 2019 study found that consumer trust in privacy and data collection was low overall, but consumers expressed the most trust in healthcare and financial services.[31] This likely reflects individuals' high expectations for the privacy of their sensitive healthcare information,

especially in communities where disability is stigmatized. It is vital to maintain this trust. Finally, for a population that is so often excluded from data collection, it is crucial to take additional measures to ensure data collection methods are accessible to avoid creating (and drawing conclusions from) biased data sets. Taken together, these factors mean that a focus on solutions cannot be at the expense of privacy or assumed to be without bias.

Data that cannot be disaggregated

Disability health data often does not allow disaggregation by impairment type, despite the fact that people with different impairments may experience different challenges when accessing healthcare. Simply asking, "Do you have a disability (yes or no)?" does not allow disaggregation. Moreover, the data cannot be used in international research because different countries have varying definitions of disability, and stigma may affect the data's reliability.[32]

In addition, impairment-specific studies are not evenly distributed. Systematic reviews of studies have shown that comparatively more data has been collected and analyzed for certain impairment types.[33] For example, 30 percent of studies assessed the relationship between COVID-19 mortality and psychosocial impairments such as depression and anxiety, while just 12 percent examined the relationship between COVID-19 and physical impairments such as loss of a limb and spinal cord injuries. Globally, no publications have examined mortality risk from COVID-19 for people with hearing or vision impairments.[34]

Likewise, a 2021 systematic review of studies comparing the uptake of breast or cervical cancer screenings for people with and without disabilities found that 47 percent of the studies examined psychiatric or mental health impairments, while just 6 percent of studies looked at functional hearing loss.[35]

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[28] Sophie Mitra and Jaclyn Yap, *The disability data report 2021*, Disability Data Initiative and Fordham Research Consortium on Disability, 2021.

[29] *The disability data report*, 2023.

[30] Matthias Evers, Lucy Pérez, Lucas Robke, and Katarzyna Smietana, "Better data for better therapies: The case for building health data platforms," McKinsey, April 15, 2022.

[31] Venky Anant, Lisa Donchak, James Kaplan, and Henning Soller, "The consumer-data opportunity and the privacy imperative," McKinsey, April 27, 2020.

[32] *The disability data report*, 2021.

[33] Hannah Kuper and Tracey Smythe, "Are people with disabilities at higher risk of COVID-19-related mortality?: A systematic review and meta-analysis," *Public Health*, September 2023, Volume 222.

[34] Ibid.

[35] Fahrin Ramadan Andiwijaya et al., "Disability and participation in breast and cervical cancer screening: A systematic review and meta-analysis," *International Journal of Environmental Research and Public Health*, August 2022, Volume 19, Number 15.

Insufficient analytics, sharing, and use of data to inform policy actions

Data collectors and other stakeholders frequently don't analyze all the data available with respect to disability, thereby missing opportunities to improve health outcomes for people with disabilities. Furthermore, a lack of global guidelines and best practices on analyzing and sharing disability data leads to substantial variability in approaches and results, in contrast to domains of global health that have embraced platforms that promote data sharing. For example, the Gateway to Global Aging Data provides access to population survey data on aging around the world, and the Dementias Platform UK acts as a comprehensive data repository on individuals with dementia in the United Kingdom.[36]

In addition, the small amount of existing research on the healthcare barriers faced by people with disabilities has not translated to effective policy design and implementation at a global level. Half of EU member states have no legislation requiring reasonable accommodation and prohibiting disability discrimination in healthcare.[37] Country evaluations from the UN Convention on the Rights of Persons with Disabilities (UNCRPD) make it clear that current efforts are inadequate to achieve equity in healthcare access for people with disabilities and that countries have not fulfilled their obligations.[38]

Ultimately, the absence of data to inform policy actions can have serious and sometimes fatal implications. For example, during the COVID-19 pandemic, some countries failed to review evidence linking certain impairments with severe COVID-19 outcomes. As a result, some people at elevated risk were not identified as such (for example, to be prioritized for vaccines), which may have resulted in unnecessary deaths.[39]

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[36] "Gateway to Global Aging Data," National Institute on Aging, accessed August 22, 2023; Sarah Bauermeister et al., "The Dementias Platform UK (DPUK) Data Portal," *European Journal of Epidemiology*, June 2020, Volume 35, Number 6.
[37] Lisa Waddington, "Prohibition of disability discrimination with regard to healthcare in the European Union," European Disability Forum, May 2021.
[38] *The Missing Billion*, July 2019.
[39] Michelle Diament, "CDC adds IDD to list of conditions at increased risk from COVID-19," Disability Scoop, March 3, 2022.

Practices to improve data collection and usage

Countries can adopt good practices in data collection and usage to create a more complete picture of the health needs and gaps of people with disabilities and use the data to conduct analysis to inform policy and program decisions.

Good practices in data collection

Several practices have proved to bolster the quality of data collection and usage[40]:

Include a disability marker in EHRs. Ideally, countries would collect disability data from EHRs covering a high percentage of the population and include identifiers of people with disabilities. This would allow policy makers and researchers to compare people with disabilities with the entire population in terms of healthcare needs, access, and outcomes. Among other advantages, analyses could be disaggregated to identify intersectional factors (such as poverty, age, sex, and impairment type) affecting people with disabilities. Although the exact determination of disability varies by country, the ability to compare detailed health information of people with and without various impairments in a given country can unlock rich insights. At present, however, most EHRs do not include a standardized disability marker, and creating one from medical records is challenging because diagnoses are recorded inconsistently and it is difficult to map an impairment (such as visual impairment) to a medical diagnosis (for example, glaucoma). Artificial intelligence could offer a solution to this problem by standardizing the way impairments are tagged and creating cohesive data sets that can be disaggregated by impairment type.

Create disability registries.[41] Registries are voluntary lists of persons with disabilities that can be connected to health data, allowing comparisons with the general population. Registries can be difficult to maintain, so they work best for this purpose if a high percentage of people with disabilities are motivated to register (for example, to qualify for benefits), which helps maintain the representativeness of the data set. Unfortunately, registries are often limited in scope and scale. They may not be integrated across all health data, so they may lack details and can become out of date. In addition, they often reflect inconsistent definitions of disabilities across and within countries, and they represent subsets of people with disabilities—for example, those with learning disabilities or receiving employment benefits (see sidebar "The benefits of granular data").

The benefits of granular data

In England, people with learning disabilities experience higher levels of unmet needs and have a shorter average life expectancy—18 years for women and 14 years for men—than the general population.[1] In 2006–07, general practitioners are asked to keep a register of people with learning disabilities.[2]

As of 2021, the voluntary registry included about 250,000 patients who had been identified and diagnosed with learning disabilities by a general practitioner.[3] NHS England calculates disability indicators at the subregional level and includes them in the registry data on key health issues such as screening, recorded disease prevalence, and prescription rates. As a result of the registry, people with learning disabilities may receive wider-ranging health benefits. For example, the registry facilitates the identification of patients who are eligible for an annual learning-disability health check and seasonal flu vaccination. Moreover, analysis of registry data has resulted in changes to the health system, including the launch of STOMP, a project intended to stop the overprescription of psychotropic medicines to people with a learning disability, autism, or both.[4] The registry in England highlights the potential benefits of collecting granular data on various impairment types.

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1. "Health and care of people with learning disabilities: Experimental statistics: 2016 to 2017," NHS Digital, December 12, 2017.
2. *People with learning disabilities in England 2015: Main report*, Public Health England, November 2016.
3. Lara Shemtob, Rathy Ramanathan, and Ken Courtenay, "Learning disability registers: Known unknowns and unknown unknowns," *British Journal of General Practice*, April 2021, Volume 71, Number 705.
4. "STOMP guidance," Coventry and Warwickshire Partnership NHS Trust, accessed August 23, 2023.

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40. A fourth method, disability-focused research, could fill gaps in disability data and help answer specific questions, but its usefulness can be limited by small sample sizes.
41. A patient registry is a collection—for one or more purposes—of standardized information about a group of patients who share a condition or experience. See "Defining patient registries and research networks" in Thomas A. Workman, *Engaging Patients in Information Sharing and Data Collection: The Role of Patient-Powered Registries and Research Networks*, Rockville, MD: Agency for Healthcare Research and Quality, 2013.

Data collectors and health systems need to recognize and address the risks associated with identifying individuals with disabilities in registries and EHRs—from both a digital identification and a data security perspective.

Conduct surveys. Nationwide censuses and household surveys, which governments often rely on to produce large data sets that inform policy decisions, may include (at most) a subset of questions on disabilities. In many cases, these surveys are not conducted frequently enough to provide timely data, a shortcoming that became apparent during COVID-19 as governments scrambled for data to inform decision making. Surveys also commonly exclude people who are institutionalized or experiencing homelessness (groups in which disability prevalence is likely to be higher). Furthermore, these surveys are often (by design) completed by a single household representative, who may lack understanding of (or fail to acknowledge) the lived experiences of household members with disabilities. Survey methods often exclude people with disabilities (for example, those who have a communication impairment and need an interpreter), and may reflect reporting bias due to the stigma associated with disabilities.

Surveys, including routine demographic surveys, can be a good starting point. They can capture a representative sample of the population and ask detailed questions about the particular and additional barriers facing people with disabilities, which are not revealed elsewhere. However, they require a significant budget, which could be a limiting factor, especially in low-income countries.

Regardless of the data collection method they are using, stakeholders can adopt the following criteria for their data:

+ current (less than ten years old)

+ nationally representative (not just regional or local)

+ inclusive of the full range of impairments

+ linked to high-quality health data such as EHRs

+ gathered using statistically valid methods:

  + study design and sampling methods that are appropriate to the study question

+ adequate sample sizes and response rates

+ consistently defined and reliable measures of disability and impairment and health outcomes

+ strong analysis, including presentation of confidence intervals

Good practices in data usage

Beyond data collection, stakeholders can also adopt good practices in data usage, including the following:

Analyze existing data sets. Unexamined disability data sets are readily available to researchers. In May 2023, the Global Health Data Exchange (GHDx) identified 2,565 data sets with indicators of health and disability, many of which have yet to be analyzed by governments, nongovernmental organizations, or others to examine the health outcomes of people with disabilities.[42]

More work could also be done to link existing data sets to uncover new insights on the health gap experienced by people with disabilities. For example, the UK Office of National Statistics created the Public Health Data Asset—a data set comprising 2011 census records, death registrations, hospital episode statistics, and primary-care records[43]—that allowed researchers to examine COVID-19-related deaths by hearing and vision impairment status. Finally, national statistics offices could expand efforts to build disability data capabilities with expertise in good practices for analysis.

Publish data. Entities that collect and report on data can prioritize publishing data sets in a timely manner (for example, within three years of collection) to improve the relevance of the analysis.

Use data to direct policies and programs. National health agencies and systems can take a targeted approach to improving health equity for people with disabilities using published data. For example, a review of national strategic plans on HIV revealed that only a few countries acknowledge the need to include disability, and none have included disability comprehensively, despite the fact that HIV prevalence is twice as high for people with disabilities.[44] National disability plans can also be used in tandem with national health plans to coordinate and guide government action, based on evidence from data.

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[42] *Reimagining health systems*, 2022; "Dataset records for disability," GHDx, Institute for Health Metrics and Evaluation (IHME), University of Washington, accessed August 23, 2023.

[43] *Reimagining health systems*, 2022; "Coronavirus (COVID-19) related deaths by hearing and vision impairment status, England methodology," Office for National Statistics, November 18, 2022.

[44] Erika Ward, Jill Hanass-Hancock, and Joseph J. Amon, "Left behind: Persons with disabilities in HIV prevalence research and national strategic plans in east and Southern Africa," *Disability and Rehabilitation*, 2022, Volume 44, Number 1.

National ministries of health can establish a disability-focused capability—for example, a department or staff member responsible for reviewing disability data and policies. According to a study by WHO, 20 percent of countries in its Western Pacific region had no disability-related capacity within their ministries of health.[45] This capability is key to create a demand for disability health data and advance the agenda of inclusive health based on evidence.

Over time, stakeholders can also explore opportunities to use artificial intelligence to close the data gap (see sidebar "Exploring how AI can help").

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45 *Rehabilitation and disability in the Western Pacific*, WHO Regional Office for the Western Pacific, 2017; "STATcompiler," Demographic and Health Surveys (DHS) Program, accessed August 23, 2023; search results for "disability," GHDx, IHME, University of Washington, accessed August 23, 2023.

Exploring how AI can help

National statistics offices and other researchers have many opportunities to use AI to advance their data collection and analysis efforts while recognizing the risks and limitations of the technology.

Data collection. Unstructured data abounds in healthcare. Researchers could collect this data from a variety of sources and convert it to structured data that could be used as inputs for traditional analysis using natural language processing.[1] Alternatively, generative AI could be used to synthesize large volumes of unstructured data—for example, from clinical notes, medical literature, treatment details, and patient-reported experiences. This type of analysis could be performed on the data directly, where allowed, or on aggregated and anonymized data sets only, which would allow researchers to draw conclusions while protecting individuals' anonymity.

AI has the potential to affect the standardization of impairment tagging in health data sets. Today, health records frequently exhibit inconsistent tags for identical impairments, posing challenges in comprehending health access and outcomes for populations with such impairments. AI can help researchers create extensive and cohesive health data sets, facilitating more-effective analyses.

Another valuable opportunity lies in gathering health data from personal and wearable digital devices such as high-tech watches and rings to create extensive disability and health data sets. To achieve this, individuals with disabilities would voluntarily identify themselves as such on their wearable devices and provide informed consent for their anonymized data to be aggregated. This approach could enable the establishment of meaningful connections between health symptoms and disabilities.

Data analysis and use. Researchers could use machine learning to uncover relationships in large health data sets (for example, between a medical condition and an impairment type). Using AI data-linking techniques, they could integrate disparate data—electronic health records, imaging data, and social determinants of health, for example—to form a comprehensive view of disability and health. They could also continually enhance data quality using algorithms to identify and address errors, inconsistencies, and missing values, leading to cleaner and more-reliable data. Finally, countries could use advanced-analytics AI to assess which national programs and policies for populations with disabilities are most effective at improving health equity.

Risks and limitations. Healthcare leaders must consider not only how to use these techniques but also the risks of doing so. For example, while AI can help reduce bias, it can also embed and scale bias.[2] If an input data set underrepresents an impairment type, the needs of people with this impairment may go undetected because AI accuracy is limited by the quality of the inputs. Finally, healthcare data is particularly sensitive. All countries should create updated legal and regulatory considerations associated with data ethics to ensure that AI-based systems are including informed consent and privacy protection in their use of health data in algorithms.

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1 Shashank Bhasker, Damien Bruce, Jessica Lamb, and George Stein, "Tackling healthcare's biggest burdens with generative AI," McKinsey, July 10, 2023.
2 James Manyika and Jake Silberg, "Tackling bias in artificial intelligence (and in humans)," McKinsey Global Institute, June 6, 2019.

Assessing maturity in data collection and data usage

Countries have made varying degrees of progress in closing the disability data gap. To explore this variability, we developed an approach to assess data collection and data usage maturity based on the strength of the methods commonly adopted. We analyzed nine countries to assess their maturity against these scales and placed the countries along two axes: data collection and data usage (Exhibit 3) (see sidebar "Research scope and methodology").

Of the nine countries assessed, only Australia and Thailand have high data maturity (an index score of 3)

across both axes. Australia has adopted all the criteria for high-quality data collection noted above. This was achieved by including unique identifiers by disability type in nationwide health information records through integration with national insurance data. As a result, the disability data set is automatically and continually updated. Australia also has adopted most of the best practices for high-quality data usage (current policies, transparent and valid analysis, many impairment domains included), although it has yet to fully translate insights into policy or regulatory actions with funding.

EXHIBIT 3

Closing the disability data gap requires improvements in data collection and usage.

Data maturity index assessment, index score of 1 to 3
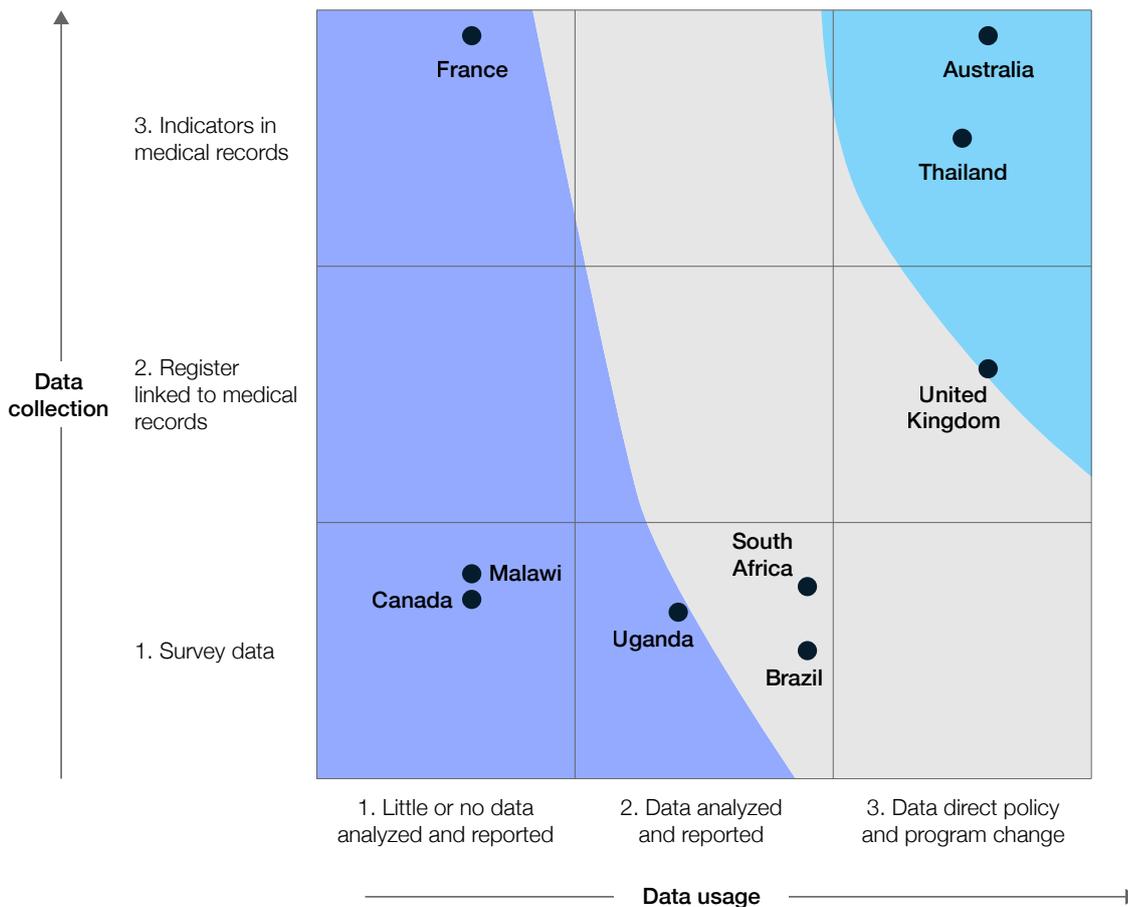
Source: Missing Billion; McKinsey Health Institute

By comparison, health information records in Brazil are neither consistent (some are electronic, while others are still stored on paper) nor aggregated nationally. Brazil conducts a national health survey every five years (most recently in 2019), while best practice is every three years or less. It also uses household sampling as a proxy for national representation. And although it asks 50 questions about functional difficulties and use of assistive devices, its methods are not internationally comparable. Brazil has relatively mature data usage practices but has not consistently translated analyzed and reported data into policy and program changes.

Canada has low maturity because it relies on survey data and has published analysis of disability and health data in only a few provinces. Malawi has low maturity because it relies on survey data alone. Many countries worldwide, regardless of income level, are likely to be in this category.

This analysis reveals that data scarcity is not limited to developing economies but is also prevalent in advanced economies. Therefore, the conventional categorization of developing versus developed nations provides only partial assistance in understanding the data landscape.

Research scope and methodology

In May 2023, we conducted a data maturity index assessment of nine countries: Australia, Brazil, Canada, France, Malawi, South Africa, Thailand, Uganda, and the United Kingdom. Research was based on more than 20 publications and websites from national statistics offices, nongovernmental organizations, ministries of health, and academic researchers. The countries were purposely selected to cover six continents, with a range of low- to high-income economies.

The maturity scale was developed based on the strength of the main data collection methods in closing the disability health data gap and how well the data is used (Exhibits 1 and 2). Countries that collect disability surveys

EXHIBIT 1

Countries can strive to attain a high level of quality (checking all five boxes) regardless of the data collection method they are using.

		What it takes to work	Quality criteria
High maturity ↑	**Health information records, including disability indicators to allow disaggregation**	Health information records (eg, health service or insurance) with a strong architecture that is a computer-based, integrated system that covers a high percentage of the population	• Data collection method is valid • Recency (rolling or ongoing) • Scale is nationally representative • Five or more impairment domains are included[1] • High-quality health data is collected[2]
	Disability register linked to health data	High percentage of the population with disabilities are encouraged to register, making the register self-maintaining	• Data collection method is valid • Recency (rolling or ongoing) • Scale is nationally representative • Five or more impairment domains are included[1] • High-quality health data is collected[2]
Low maturity	**Survey data, including routine demographic surveys**	Routine national data collection that covers a high percentage of the national population Budget dedicated to disability surveys	• Data collection method is valid • Recency (< 10 years old) • Scale is nationally representative • Five or more impairment domains are included[1] • High-quality health data is collected[2]

[1]For example, intellectual, physical, sensory, mental, and social impairments.
[2]High-quality health data is accurate, complete, and relevant data that describes healthcare access and outcomes.
Source: *Disability Data Review: A collection and analysis of disability data from 40 countries*, Leonard Cheshire and UK Aid Direct, July 24, 2018; *Malawi Multiple Indicator Cluster Survey (MICS) 2019-20: Survey findings report*, Malawi National Statistical Office, 2021

were ranked as low maturity, those with disability registries connected to health data are medium maturity, and countries that use electronic health records with a disability tag are high maturity. Where two data collection methods are used, the higher-maturity approach was selected. For data usage, not analyzing the data collected is low maturity, analyzing and sharing data is medium maturity, and using it to inform and change policy is high maturity. Within each maturity level (low, medium, and high) are subcriteria based on data quality (for example, the degree to which the data is nationally representative). The research was assessed by a team of regional McKinsey healthcare experts and academics in each of the nine countries.

EXHIBIT 2

The most mature countries not only analyze and report data but also use it to inform policy making and program decisions.

		What it takes to work	Quality criteria
High maturity	**Data is analyzed, reported, and used to direct policy and program changes**	Department or staff member in the health department or ministry is responsible for reviewing disability data Funding is allocated to implement suggested changes to policies and programs	• Policies were reviewed recently • Policy or regulation translates to action with necessary funding • Data analysis method is transparent and valid • Scale is nationally representative • Many impairment domains are included
	Data is analyzed and reported but not directly translated into policy and program changes	Funding allocated to disability data analysis Alignment on best practices for data analysis	• Data is analyzed and published within three years of collection • Publications and raw data are easily accessible • Data analysis method is transparent and valid • Scale is nationally representative • Data is disaggregated by impairment type
Low maturity	**Data is collected but little (or none) is analyzed and published**	At least level 1 maturity on data collection scale	

Source: *Disability Data Review: A collection and analysis of disability data from 40 countries*, Leonard Cheshire and UK Aid Direct, July 24, 2018

A call to action

Overcoming the disability health data gap will entail a coordinated and committed effort by relevant stakeholders (Exhibit 4).

The gap in disability data presents a substantial barrier to achieving health equity. Without accurate and comprehensive data, all stakeholders are limited in their ability to address the needs and challenges faced by this large share of the global population. It is crucial for healthcare organizations, governments, donors, implementers, and other stakeholders to prioritize the collection and use of data as a fundamental step toward achieving equitable healthcare for all. By doing so, we can work toward a future in which individuals with disabilities receive the care and support they need, enabling them to lead healthier, more fulfilling lives. In an upcoming report, we will discuss opportunities for the public and private sectors to play a role in improving healthcare accessibility.

EXHIBIT 4

Different stakeholder groups can take specific actions to overcome the gap in disability health data.

Stakeholder	Key action	Maturity level achieved by action
Governments and healthcare organizations, including insurers and private health providers	Insist on inclusion of disability questions on health surveys and censuses, including a funding line and requirement to report against it	Low
	Analyze and publish existing relevant data sets	Low
	Build capabilities in the national statistics office to collect and analyze disability data	Medium
	Link disability registers to health data to allow disaggregation	Medium
	Integrate disability indicators with medical records to allow disaggregation, particularly as health information systems are digitalized over the next 10 years	High
	Establish a disability-related representative in the national health department or ministry who is responsible for ensuring that health-related policy actively targets inclusion of people with disabilities	High
Donors or funders	Fund technical assistance and analytical capacity for national disability and health surveys	Low
	Fund research and advocacy to align on best practices for data collection and analysis, including the criteria for a person to be determined as having a disability	All levels
Implementers, including NGOs[1] and organizations for people with disabilities	Run and analyze disability and health surveys to fill gaps where there is no data	Low
	Advocate with governments on the importance of disability and health data collection and usage	Low

[1] Nongovernmental organizations.
Source: Missing Billion; McKinsey Health Institute