MISSING BILLION

Reimagining Health Systems

That Expect, Accept and Connect 1 Billion People with Disabilities

A FOLLOW-ON TO THE FIRST MISSING BILLION REPORT

SEPTEMBER 2022

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In 2019, the first Missing Billion report 'Access to health services for 1 billion people with disabilities' was published. In 2020, Hannah Kuper, Phyllis Heydt, Ola Abu Alghaib and Mari Tikkanen launched the Missing Billion initiative*.

For more information please visit: www.themissingbillion.org

*The Missing Billion is to indicate that the one billion people with disabilities are missing out on equitable healthcare access. We do not imply that this group is Missing.

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> "Including the experiences and skills of people living with disabilities in the design and delivery of health systems is fundamental to achieving Health For All."[1]
>
> **DR. TEDROS ADHANOM GHEBREYESUS**
> DIRECTOR GENERAL, WORLD HEALTH ORGANIZATION

[1] Dr. Tedros [@drtedros]. 2022, January 4. Twitter.

Expect. Accept. Connect.

Executive Summary

Context

There are more than one billion people with disabilities worldwide. That is 15% of the world's population. People with disabilities often have greater health needs but experience more barriers to accessing care because of health systems failures at all levels. As a result, people with disabilities frequently have poorer health outcomes. This inequality was recently highlighted during the COVID-19 pandemic – for example, in the United Kingdom, people with disabilities made up 16% of the population but 59% of people who died of COVID-19.

The world is moving beyond the pandemic towards "building back better" health services and systems. This *must* include people with disabilities as: 1) health targets will not be achieved by 2030 if this large population continues to be left behind, including Universal Health Coverage (UHC) and Sustainable Development Goal 3 (SDG 3); 2) people with disabilities have the right to healthcare, and healthcare contributes to their ability to live a good life; and 3) inclusive health systems work better for everyone. It is therefore critical for the global community to reimagine how health systems should be designed to be inclusive of people with disabilities.

This Report

The first Missing Billion report from 2019 highlighted the health inequities and access challenges that people with disabilities face around the world. It raised awareness among global health actors about the widespread health systems failures that people with disabilities experience. The report concluded that people with disabilities should be recognized as a key population, that there is a need for a long-term strategic approach on disability inclusion, and that immediate action are required to improve health services and address specific access barriers.

This second report builds on the previous work and describes a clear pathway for action towards defined disability-inclusive health systems. This report has the following objectives:

- Present **new insights on health outcomes and health system gaps for people with disabilities** via newly analyzed data from nearly 900,000 children and adults, including 65,000 with disabilities, across 37 low-and middle-income countries, and 3 new systematic reviews.
- Present **a vision for health systems that are designed to be fully inclusive**, using human-centered design and crowdsourcing to highlight the lived experiences of people with disabilities at all stages of the health system; giving voice to their concerns and presenting actionable responses to attain an inclusive health system.
- Translate this vision into **a practical Missing Billion road map** to 2030 with targets and proposed actions for key stakeholders.

Contents

This report contains the following sections:

Key messages from this report

- People with disabilities have **2.4-fold higher mortality rates** than those without disabilities and are missing 10 to 20 years of life expectancy. They also face poorer health outcomes across SDG 3 indicators. By designing health systems that prioritize inclusive health services for people with disabilities, we can **reduce the life expectancy gap of people with disabilities**.

- Health Systems that include people with and without disabilities must **expect**, **accept**, and **connect** people with disabilities to quality care. Service delivery and underlying system functions must be intentionally designed to include people with disabilities.

- To reduce the life expectancy gap between people with and without disabilities, global health actors and country governments should **develop inclusive health programs and systems through institutional leadership** involving disability-inclusion and disability-focused budget lines, plans and monitoring.

- We urge global health actors, country governments and stakeholders to collaborate to achieve disability inclusion by the key sectors involved in healthcare delivery. The **"4 Million Targets"** are proposed as a set of minimum targets that can guide a concerted and multi-sectoral effort towards reducing the life expectancy gap by 2030. We encourage stakeholders to refine and expand these targets for an ambitious roadmap with measurable short- and medium-term goals.

OBJECTIVES	THE 4 MILLION TARGETS BY 2030
Autonomy: People with disabilities make informed decisions about health care and are aware of their rights and options	**1 million** additional people with disabilities are champions for their right to healthcare
Affordability: People with disabilities can afford to access health services	**1 million** additional people with disabilities in low-and middle-income countries access health insurance and/or social protection
Human resources: Health-care workforce is knowledgeable about disability and has the skills and flexibility to provide quality care to people with disabilities	**1 million** additional health workers trained on disability
Health facilities: Health-care services, including health-care facility infrastructure and information, are accessible for people with disabilities	**1 million** health facilities audited and an additional 10,000 are inclusive

To contribute to these 4 Million Targets, we urge countries to pledge for:

GOVERNANCE	LEADERSHIP	HEALTH FINANCING	DATA & EVIDENCE
Disability-inclusive national health plans	Institutional leadership for disability-inclusive health	A health budget line for disability	Disaggregated health data by disability

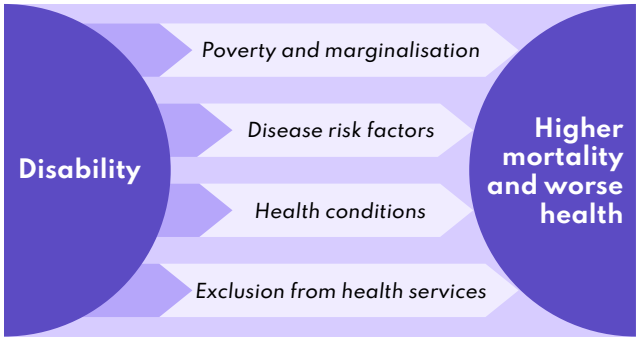
1. Awareness of the need for equitable health access is growing

Building on the data presented in the first Missing Billion report, disability inclusion is pathway critical for the achievement of the global health agenda and is better for all. Since the launch of the Missing Billion report in 2019, momentum and policy recognition has been building to tackle this issue.

Inclusion of one billion people with disabilities is critical to achieving the global health agenda

There are one billion people with disabilities globally. This number is set to increase further with population growth, ageing populations, a shifting disease burden, armed conflict, and global climate and health crises.[2] The first Missing Billion report, which was published in 2019, showed that people with disabilities face higher healthcare needs, more barriers in accessing services and less health coverage, resulting in worse health outcomes across SDG 3 indicators. This is exacerbated because of their marginalized position in society, monetary poverty,[3] and underlying health condition. This pattern is seen across the world and for people with different impairment types.

How disability leads to higher mortality and poor health



UN Convention on the Rights of Persons with Disabilities defines disability as "long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." People with disabilities are not a homogenous group, and the experiences of individuals will be influenced by their impairment type, gender, age, family support, environment, and so on.

The right to quality healthcare for people with disabilities is enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD)[4] and in the laws of many countries. According to article 25 of UN CRPD, "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation."

Policy recognition of disability-inclusive health

Since the publication of the first Missing Billion report, there has been momentum and policy recognition around the importance of disability-inclusive health internationally.

This momentum is also seen within countries as a growing number of governments have prioritized equitable health-

[2] World Health Organization & World Bank. 2011. World report on disability.
[3] Banks et al, 2017, Poverty and disability in low- and middle-income countries: A systemic review. PLoS One
[4] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Momentum at the global level:

care for people with disabilities. For instance, new national policies and laws on disability in Uganda (2020), Zambia (2021) and Zimbabwe (2021) aim to increase access to quality healthcare and services at all levels for people with disabilities.[8,9,10] The United States government, as part of the Build Back Better Framework in 2021, invested in Medicaid improvements for affordable, high-quality home healthcare services for older Americans and people with disabilities.[11]

Funders and multi-lateral agencies are also making disability-inclusion a priority in development efforts. For example, the German Federal Ministry for Economic Cooperation and Development (BMZ) launched a cross-sectoral strategy paper in 2019 on *Inclusion of persons with disabilities in German development cooperation.* The paper sets out binding requirements for German development cooperation regarding the inclusion of people with disabilities. The Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) is leading the Global Project on Inclusion of Persons with Disabilities to support innovative approaches to implement this strategy in partner countries. In 2022, the UK launched the *Foreign, Commonwealth & Development Office disability inclusion and rights strategy 2022 to 2030* which aims to ensure that people with disabilities everywhere can access and use affordable, accessible, and quality health services throughout their life so they can make and act on informed decisions about their own health.[12] UNICEF's *Practice Guide: Inclusion of children and young people with disabilities in routine general health care* seeks to drive improvements in availability, accessibility, acceptability, affordability and quality across UNICEF's health programs, also providing a base for efforts to strengthen disability-inclusive primary healthcare and health systems.

This momentum is promising, but more is needed to achieve good health for all by 2030 and ensure that we Leave No One Behind. All stakeholders have a responsibility to design their programming and funding strategies to be inclusive of people with disabilities.

[5] World Health Assembly Resolution 74.8, 2021
[6] European Commission, 2021, Strategy for the Rights of Persons with Disabilities.
[7] Pre-Summit meeting on Disability Inclusion in the Health Sector.
[8] Republic of Zambia, 2021, National Disability Policy.
[9] Uganda, Persons with Disabilities Act, 2020.
[10] Zimbabwe, National Disability Policy, 2021.
[11] The White House. 2021. The Build Back Better Framework.
[12] FCDO Disability Inclusion and Rights Strategy 2022 to 2030.

2. The urgent need for disability-inclusive health systems

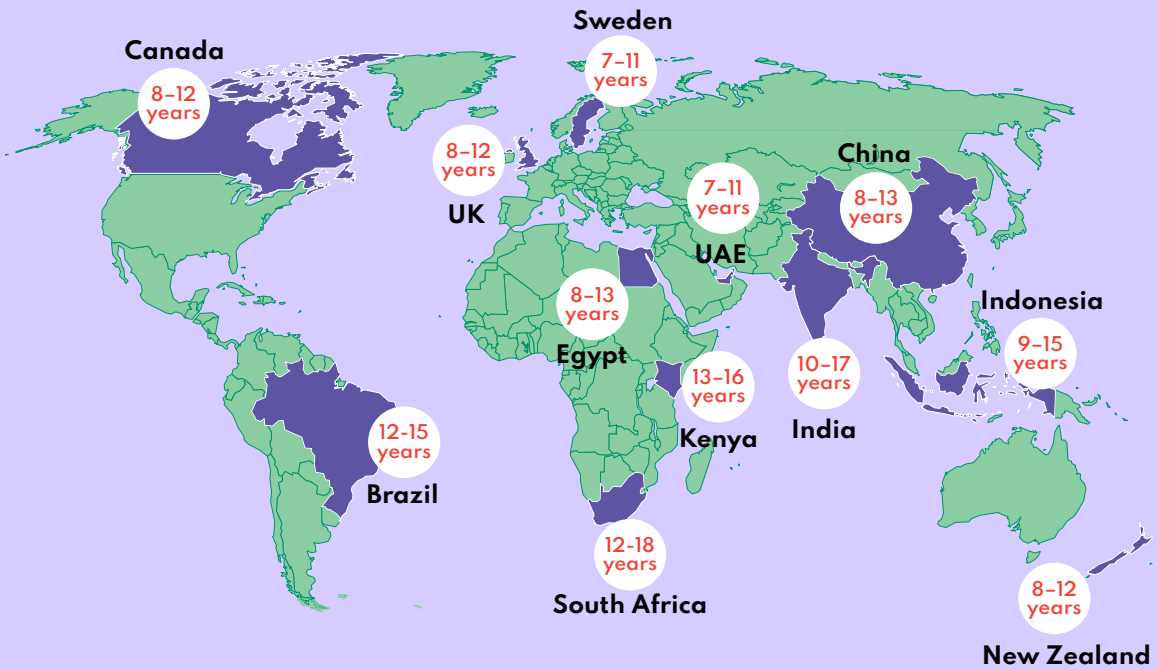
Building on the data presented in the first Missing Billion report, new evidence analyzed for this report highlights the large, urgent need for inclusion of people with disabilities. The life expectancy gap is substantial: mortality rates are at least two times higher for people with disabilities. This translates into a life expectancy gap of 10-20 years. These inequalities will become worse as disease profiles shift towards noncommunicable diseases. Closing the gap is possible, but simple solutions and improvements are not yet actioned. A better vision on how health systems can ensure equal and equitable health access is urgently needed.

For this report, our team generated new evidence by: (1) analyzing data from nearly 900,000 children and adults from UNICEF Multiple Indicator Cluster Surveys (MICS), including 65,000 people with disabilities, across 37 low-and middle-income countries; and (2) undertaking three new systematic reviews.

People with disabilities have dramatically higher mortality rates

A systematic review of 65 studies from low and middle-income countries finds that people with disabilities had 2.4 times higher mortality rates than people without disabilities. This impact was observed across age groups and the whole spec-

Life expectancy gap estimates for 12 countries based on modelling:



The results from the systematic review of increased mortality associated with disability were used to model the life expectancy reductions using a Life Table Approach (publication in preparation).

trum of impairment types. Increased mortality rate means lower life expectancy. Indeed, data on life expectancy and disability from nine studies (Appendix Table 1.1), as well as modelling across 12 countries as well as globally),[13] shows that life expectancy is often 10-20 years lower for people with disabilities.

The COVID-19 pandemic exemplified this trend. A systematic review of 37 studies across 11 countries showed that people with disabilities were **2.8 times more likely to die from COVID-19 than their peers without disabilities globally.** These estimates were adjusted for many risk factors, like poverty, and so the true relationship is likely to be even stronger. For example, in the United Kingdom (UK), people with disabilities made up 16% of the population, but 59% of people who died of COVID-19.[14] Robust data from low-and middle-income countries related to this topic are lacking. Studies from different countries, such as UK, USA and Canada show that people with intellectual disabilities, especially those with Down syndrome, appear at the highest risk for dying from COVID-19. More details can be found in Annex.

These are often preventable deaths and gaps in life expectancy that can be closed by long-term investments in accessible, affordable, and quality healthcare. For instance, UK data showed that the life expectancy gap was 13 years for men with intellectual disabilities and 20 years for women with intellectual disabilities. 37% of avoidable deaths in people with intellectual disabilities were from causes amenable to change by good quality healthcare, while this was only 13% in the general population.[15]

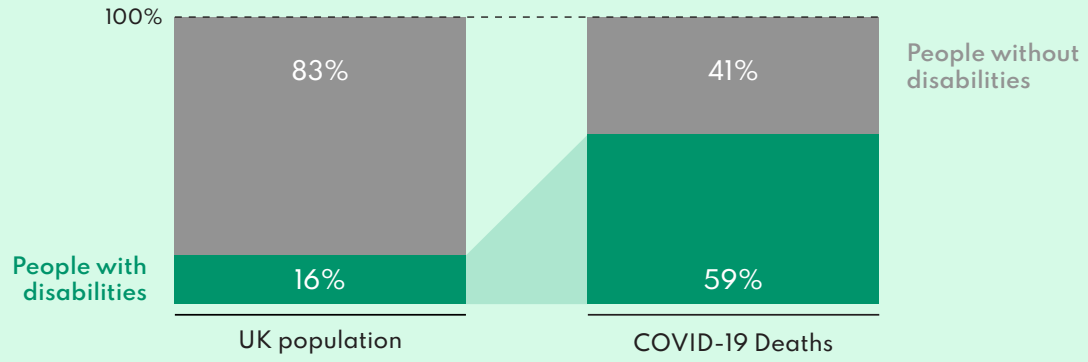
New evidence highlights the health gaps experienced by people with disabilities

The first Missing Billion report showed that people with disabilities on average have worse health status. New analysis conducted by the authors of this report using the UNICEF MICS indicators by disability status expands on these points. The work presented in this report represents the most comprehensive analysis to date, covering data from 37 low-and middle-income countries that were conducted between 2016 and 2020 and including 465,433 children aged 2-17 (50,951 with disabilities) and 428,685 adults aged 18-49 (15,228 with disabilities).

These new findings are supported by existing literature showing that on average people with disabilities have:

- **Lower population coverage of healthcare:** e.g. overall, sexual and reproductive health services,[16] menstrual hygiene management,[17] dental care;[18]

COVID-19 deaths in relation to disability in the UK



Source: ONS, Coronavirus (COVID-19) related deaths by disability status, England and Wales"

[13] We used life tables to estimate what the impact of higher mortality among people with disabilities has on life expectancy. For instance, using data from the United Kingdom, a 2-fold increase in mortality rates across the age groups translates into a life expectancy reduction of 7 years (78 to 71). A 3-fold increase in mortality means 21 years of life expectancy lost.

[14] ONS. 2021. COVID-19 and the impact on disabled people.

[15] Heslop et al. 2013. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. The Lancet.

[16] Hameed et al. 2020. From words to actions: systematic review of interventions to promote sexual and reproductive health of persons with disabilities in low- and middle-income countries. BMJ Global Health.

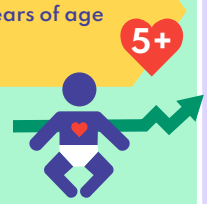
[17] Wilbur et al. 2019. Systematic review of menstrual hygiene management requirements, its barriers and strategies for disabled people. Plos One.

[18] Bright et al. 2018. A Systematic Review of Access to General Healthcare Services for People with Disabilities in Low and Middle Income Countries. International Journal of Environmental Research and Public Health.

Results of the new health outcomes data (by SDG 3 targets):

CHILD HEALTH

TARGET 3.2: End preventable deaths under 5 years of age



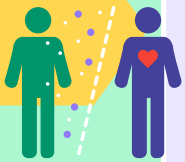
Children with disabilities are at a higher risk of common causes of under-5 mortality. The percentage of children that reported experiencing the following conditions in the past two weeks:

	With disabilities	Without disabilities	Relative higher risk for disabled children
Acute respiratory infection	**34/100**	27/100	+26%
Fever	**28/100**	23/100	+22%
Diarrhea	**18/100**	13/100	+38%

According to MICS data, treatment levels are similar between children with and without disabilities.

HIV/AIDS

TARGET 3.3: End the AIDS epidemic



Adults with disabilities are lagging in the HIV response:

- Adults with disabilities were less likely to have comprehensive knowledge about HIV prevention and transmission (21%) compared to people without disabilities (28%). This gap is particularly large in Sub-Saharan Africa: 23% versus 33%.
- Adults with disabilities appear less likely to have ever been tested for HIV compared to those without disabilities in Sub-Saharan Africa (41% versus 44%) and Latin America (63% versus 65%).

Other studies show lower adherence to antiretroviral therapy[19] for people with disabilities.

FAMILY PLANNING

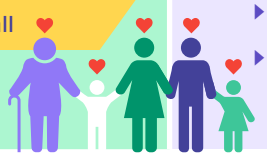
TARGET 3.7: Ensure universal access to sexual and reproductive healthcare services

Women with disabilities are behind in modern contraceptive use:

- Lower coverage of modern contraceptives in women with disabilities (44%) than women without disabilities (48%). This difference was particularly large for women in South Asia: 48% versus 59%.

IMMUNIZATION

TARGET 3.8: Achieve universal health coverage, including vaccines for all



Children with disabilities are generally at greater risk of missing out on vaccinations. Previous UNICEF analyses[20] show:

- Lower basic vaccination coverage in children aged 24 to 35 months with disabilities compared to children without disabilities: 56% fully vaccinated versus 58%.
- Among children with multiple functional impairments, only 44% were fully vaccinated.
- Immunization levels were lowest among children with multiple disabilities in the poorest wealth quintile (34%) and children living in rural areas (40%).

- **Inadequate range of health services provided:** Frequently cannot obtain the disability-related services they need, like rehabilitation and assistive technologies;[21,22]
- **Higher healthcare expenditure:** 50% more likely to face catastrophic health expenditures;[23]
- **Poorer quality care.**[24,25,26]

People with disabilities are therefore falling behind in the key components of UHC.

The new MICS analyses that we conducted also show challenges in early development for children with disabilities, which will impact on their capacity across the life-course. **Early Childhood Development Index scores were substantially lower in children with disabilities**.

[19] Carpenter et al. 2020. Looking at ART adherence through a disability lens. Disability and Rehabilitation.

[20] UNICEF, 2021. Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

[21] Bright et al. 2018. A Systematic Review of Access to Rehabilitation for People with Disabilities in Low- and Middle-Income Countries. International Journal of Environmental Research and Public Health.

[22] Danemayer et al. 2022. Estimating need and coverage for five priority assistive products: a systematic review of global population-based research. BMJ Global Health.

[23] World Health Organization and World Bank. 2011. World Report on Disability.

[24] Bourne et al. 2021. Healthcare inequities among adults with developmental disability: An integrative review with implications for nursing education. Nurse Education in Practice.

[25] Stirling et al. 2021. A scoping review documenting cancer outcomes and inequities for adults living with intellectual and/or developmental disabilities. European Journal of Oncology Nursing.

[26] Hashemi et al. 2022. Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. Disability and Rehabilitation.

CASE IN POINT: Reaching UNAIDS 95-95-95 fast-track targets by 2030

The failure to reach health targets can be illustrated through HIV. A lack of disability inclusion can impede the achievement of the UNAIDS 95-95-95 targets. At least one in four people living with HIV have disabilities.[27] This is because people with HIV are more likely to develop impairments (e.g. hearing loss) as a result of concurrent infections, ARTs and/or the direct effect of the virus.[28] People with disabilities are also more likely to contract HIV, due to their marginalized position in society, more prevalent sexual risk factors, and barriers to accessing services and information.[29] We also demonstrated earlier in this report that people with disabilities are less likely to be tested for HIV or to adhere to HIV treatment.

Modelling shows that this **exclusion of people with disabilities will make it very difficult to reach UNAIDS 95-95-95 targets by 2030:**

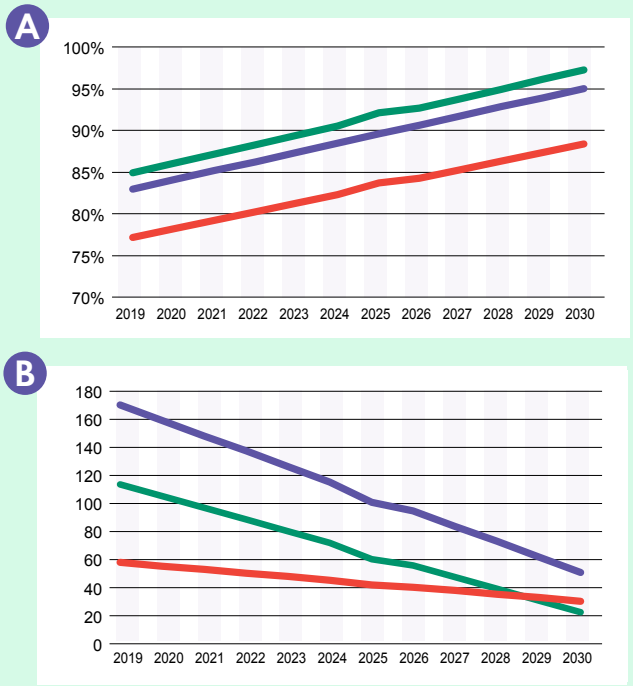
- Achieving 95% of people living with HIV know their HIV status means that 97% of HIV-positive people without disabilities would need to know their status to compensate for only 88% of HIV-positive people with disabilities who have been tested.
- Achieving 95% of people on treatment with suppressed viral loads means that 99% of HIV-positive people without disabilities would need to adhere to treatment to compensate for adherence reaching only 88% among HIV-positive people with disabilities.

These models also show that by 2030, the majority of people who have not met the targets will be people with disabilities.

Without a focus on disability, by 2030, we will not achieve UNAIDS 95-95-95 targets.

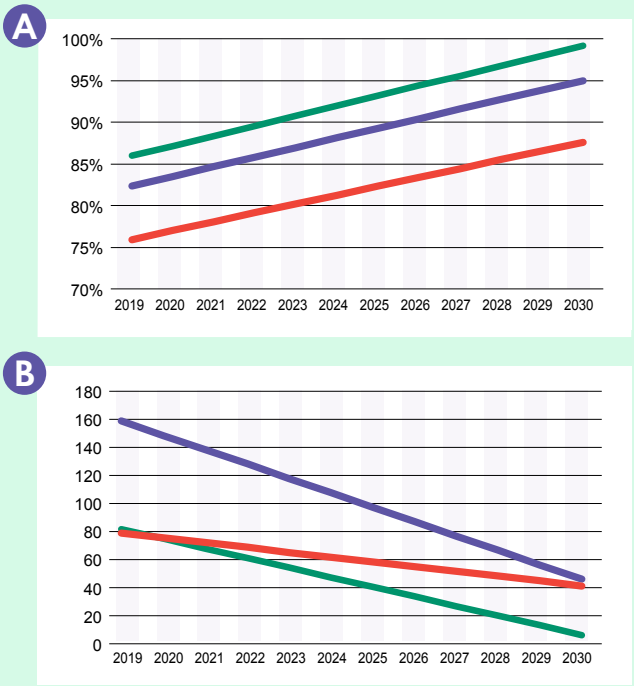
Modelled estimates of the proportion of people living with HIV in Tanzania, by disability (2019–30)

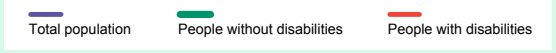
(A) Proportion of people with HIV who are aware of their HIV status. (B) Number of people with HIV who are unaware of their HIV status per 1000 individuals with HIV. Data from Tanzania.



Modelled estimates of the proportion of people living with HIV in South Africa, by ART status and disability (2019–30)

(A) Proportion of people with HIV on ART. (B) Number of people not on ART (per 1000 people with HIV). Data from South Africa. ART = antiretroviral therapy.





[27] Banks et al. 2015. The relationship between HIV and prevalence of disabilities in sub-Saharan Africa. TMIH.

[28] Kuper et al. 2022. A focus on disability is necessary to achieve HIV epidemic control. The Lancet HIV.

[29] De Beaudrap et al. 2017. Prevalence of HIV infection among people with disabilities. The Lancet HIV.

Overall, only 38% of children with disabilities achieved an adequate score, compared to 56% of children without disabilities. This pattern was observed across all geographic regions, although the discrepancy was particularly big in the Middle East (41% versus 76%) and South Asia (37% versus 69%). Levels of stunting were higher among children with disabilities (39% versus 32%), across most geographic regions. Levels of wasting were higher among children with disabilities (8% versus 5%). This gap was most obvious in East Asia (7% versus 3%) and sub-Saharan Africa (8% versus 6%). These gaps persist as disability funding declined between 2007 and 2016, and only 2% of the estimated USD 79.1 billion invested in early childhood development during this period was spent on disabilities. Meanwhile, children with disabilities are routinely excluded from early child development programs, despite their greater need.[30]

People with disabilities are at higher risk for non-communicable diseases:

CANCER RISK

Different sources of evidence show that people with disabilities are at higher risk of cancer diagnosis and death, compared to people without disabilities:

- **Sweden:** People with intellectual disabilities were 3.6 times more likely to die from cancer.[31]
- **Korea:** Women with disabilities were more likely to be diagnosed with cervical cancer (16% versus 7%), and mortality rates were higher.[32] This pattern was also seen for lung cancer[33] and gastric cancer.[34]
- **Netherlands:** People with intellectual disabilities were 1.5 times more likely to die from cancer.[35]
- **USA:** Women with disabilities experienced higher cervical and breast cancer rates.[36]

CANCER SCREENING AND TREATMENT

Our new systematic review of 29 studies from 7 countries showed that women with disabilities were 25% less likely to have been screened for breast cancer and 37% less likely to have been screened for cervical cancer compared to their non-disabled peers.[37]

Other studies and reviews confirm these patterns, showing:

- Lower uptake of other types of cancer screening, including colorectal cancer screenings (25% lower), in people with disabilities[38]
- Greater difficulty experienced by people with disabilities with receiving quality cancer care[39]
- Together, this evidence shows that people with disabilities will experience higher cancer fatality rates, which could be avoided through more inclusive services. For instance, data from Korea showed that women with disabilities who had localized cervical cancer were 26% more likely to die, compared to patients without disabilities, and this was due to differences in cancer stage, treatment, and socio-economic factors.[35]

DIABETES

It is already established that people with disabilities are more likely to have diabetes, but they also have worse diabetes care:

- **Korea:** over 2 times as likely to have diabetes-related avoidable hospitalizations in people with severe disabilities.[40] This risk was particularly elevated in people with intellectual or psychosocial disabilities.
- A systematic review showed that people with intellectual disabilities and their caregivers have less understanding of diabetes, and there is little emphasis on self-management by the person with disabilities.[41]

[30] Smythe et al. 2021. Early intervention for children with developmental disabilities in low and middle-income countries – the case for action. International Health.

[31] Hirvikoski et al. 2021. Association of intellectual disability with all-cause and cause-specific mortality in Sweden. JAMA Network Open

[32] Choi et al. 2021. Disparities in the diagnosis, treatment, and survival rate of cervical cancer among women with and without disabilities. Cancer Control.

[33] Shin et al. 2019. Disparities in the diagnosis and treatment of lung cancer among people with disabilities. Journal of Thoracic Oncology.

[34] Kim et al. 2020. Disparities in the diagnosis and treatment of gastric cancer in relation to disabilities. Clinical and Translational Gastroenterology

[35] Cuypers et al. 2022. Cancer-related mortality among people with intellectual disabilities. Cancer.

[36] Iezzoni et al. 2021. Association between disability and breast or cervical cancer, accounting for screening disparities. Medical Care

[37] Andiwijaya et al. 2022. Disability and Participation in Breast and Cervical Cancer Screening: A Systematic Review and Meta-Analysis. International Journal of Enviromental Research and Public Health.

[38] Floud et al. 2021. Disability and participation in breast and bowel cancer screening in England: a large prospective study. British Journal of Cancer.

[39] Iezzoni. 2022. Cancer detection, diagnosis, and treatment for adults with disabilities. The Lancet Oncology.

[40] You et al. 2022. Disparities in diabetes-related avoidable hospitalization among diabetes patients with disability using a nationwide cohort study. Scientific Reports.

[41] MacRae et al. 2015. Diabetes in people with intellectual disabilities: A systematic review of the literature. Research in Developmental Disabilities.

On the other side, the analysis shows some positive trends for maternal health: there were similar levels of antenatal care coverage, institutional deliveries, and qualified antenatal providers for women with and without disabilities. However, we must be cautious as these results do not capture differences in the quality of the birth and other antenatal experiences, including whether the preferences of women were respected.

There are also other examples from the analyses where there were no observable discrepancies in coverage between people with and without disabilities. However, for some of these statistics the sample size is small, for instance malaria treatment, and again, these overall figures may conceal differences in quality, cost, and acceptability of services.

The healthcare inequities will worsen as disease profiles shift

People with disabilities are more likely to experience non-communicable diseases. This will be a growing concern as there is an epidemic shift from infectious to non-communicable diseases in the coming decades. We can demonstrate this pattern using cancer and diabetes as examples.

Addressing these gaps: solutions exist but action is needed

Health insurance offers an effective means at improving healthcare access. People with disabilities should be prioritized for coverage, as they have higher healthcare needs yet greater poverty levels. National health plans often do not specifically mention people with disabilities and very few health insurance schemes and approaches exist to help with financing gaps for people with disabilities.[42] Our analyses shows no major difference in health insurance coverage between people with and without disabilities in adults (38% versus 39%) or in children (children aged 2-4: 12% versus 11%; children aged 5-17: 20% versus 21%). This finding is consistent with the limited data available on this topic.[43]

These data highlight both the inequities in health faced by people with disabilities, and the missed opportunities for action. A vision is needed of what it means to have health systems that are fully inclusive to support countries to move towards disability-inclusive health services. This vision must be guided by and based on the needs and desires of people with disabilities.

Online Data Dashboard

The complete results of our analysis using the UNICEF MICS analysis, as well as additional data from systematic reviews have been visualized into an interactive dashboard available at **www.themissingbillion.org/data-dashboard**

The dashboard offers:

- a view of indicators by country, regional and global estimates;
- disaggregated data by sex and type of impairment when available;
- a tool to compare data for up to three countries.

[42] Walsham et al. 2019. Social protection for people with disabilities in Africa and Asia. Oxford Development Studies

[43] V Hees et al. 2019. Leaving no one behind? Social inclusion of health insurance in LMICs. International Journal for Equity in Health.

3. Designing a vision for disability-inclusive health systems

People with disabilities have described a vision of inclusive health systems as one in which they are **expected**, **accepted**, and **connected** to receive quality care. This vision centers around the idea of the system being prepared to provide quality services to people with disabilities in a respectful, predictable, and comprehensive manner. This reimagined health system will reduce the barriers and stressors that people with disabilities may face when navigating how to seek care and will also improve their health outcomes.

A Human-centered design approach to re-imagine health systems

One of the guiding principles in disability-inclusive development is that changes must be informed by people with disabilities to be appropriate, acceptable and contextually relevant. Here, we take the next step to reimagine healthcare that is inclusive. We used a participatory and human-centered design approach to co-create a vision for inclusive health systems that was informed by more than 400 people with disabilities and their families or caregivers from different geographic regions, ages, genders, impairment

> "People who face a particular challenge are the key to solving it. Change is going to happen when we shift the power of decision making."
>
> **PARTICIPANT WITH DISABILITIES FROM DESIGN WORKSHOP, KENYA**

Experiences of people with disabilities when accessing health services

	A I perceive a need	B I decide to seek healthcare	C I reach the healthcare venue	D I access healthcare services	E I engage with healthcare staff	F I receive treatment and follow up care
What people with disabilites experience	**Uncertain about symptoms and whether or not to seek care** *"I was used to having frequent headaches and was so conditioned to the pain that I did not realise when to seek help. We only got to know about the tumour when it was at a later stage."* ADOLESCENT WITH LOW VISION	**Concerned about the quality and accessibility of care I will receive** *"I always have to take someone along when I go to a healthcare service for the first time because I worry that they will not understand me and think I have a mental disability and I will be put into an asylum."* OLDER PERSON WITH CEREBRAL PALSY AND SPEECH IMPAIRMENT	**Unable to access 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."* GIRL WITH PHYSICAL IMPAIRMENT, AND HER FATHER	**Not able 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	**Not treated comprehensively or with respect by staff** *"The doctor couldn't understand that I was pregnant. I was given pain medication for stomach ache and sent home."* WOMAN WITH HEARING IMPAIRMENT	**Confused about what to do after the visit** *"I had to rely on my faltering memory to remember the information given. I was too intimidated by the doctor to ask for his time again to confirm."* MAN WITH VISUAL IMPAIRMENT
What people with disabilites want	Everybody is equipped to access care in their own settings	Everybody is informed about what they can expect at a healthcare service	Basic minimum standard of healthcare is within reach and affordable for all	Everybody receives healthcare in an environment that accommodates for their abilities	Everybody's needs are comprehensively understood and mindfully addressed	Everybody is equipped to determine and protect themselves from risk and identify

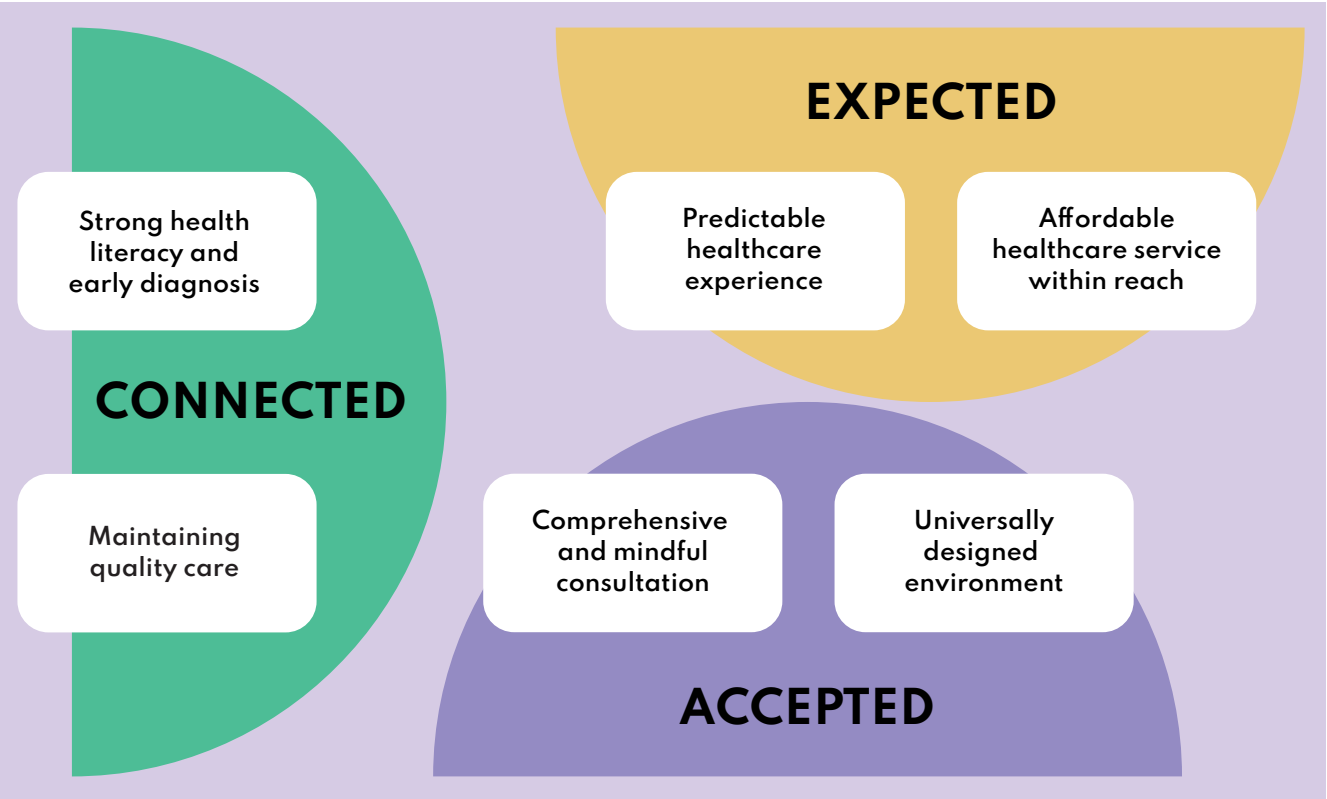
types and health seeking needs. We worked with people with physical, sensory, intellectual, and neurological impairments to understand their needs, desires, and expectations for an inclusive health system. This included interviews with people from Africa, North and South Americas, and Asia, an in-person workshop in Mumbai, an online workshop with participants from various countries across Asia, Africa, and Europe, and further engagements through social media.

A clear pattern emerged highlighting the compounded levels of difficulty and concern that people with disabilities experience when accessing healthcare.

People with disabilities expressed a re-imagined vision for healthcare as one where they are:

- **EXPECTED:** Services are provided in settings that suit people with disabilities, and facility-based care is accessible and affordable. Participants can access health services in ways convenient to them, either through tele-health consultations, home visits, or in-person at an accessible facility when required. Participants viewed their ideal system as one where they could anticipate how to navigate their visit: how long the consultation will take, what transport options will be reliable, how much the service will cost, what procedures will take place, if accessible equipment will be provided, and if instructions will be given in accessible formats. Being able to ask questions and plan is critical.
- **ACCEPTED:** People with disabilities are welcomed and provided with quality care by trained and motivated staff regarding disability. Having facilities and staff that are prepared for people with disabilities helps to reduce access and communication barriers and respect patients' dignity and privacy. Participants drew parallels from analogous positive examples such as airports who have trained staff, wheelchairs on hand, and printed language on the ticket stating the accessibility needs of the person with disabilities.
- **CONNECTED:** Referrals and accessible follow-up care are given after healthcare visits with connection and coordination across the entire healthcare journey. People with disabilities expressed wanting accessible health information in communities for identifying symptoms, to reaching the healthcare venue through reliable transportation, to encountering friendly staff who provide care in tailored formats, to clear instructions for after-care and connections to other services and people with similar conditions.

Components of inclusive health services



The components of disability-inclusive health services

1 Strong health literacy and early diagnosis

"We didn't know he was sugar intolerant for months, we need to be able to detect a problem, he isn't able to share on his own."

GUARDIAN OF YOUNG PERSON WITH AUTISM, INDIA

"I went for a regular checkup. They took my blood and they told me I had cancer. You go to the doctor for something else and when you're there you know."

OLDER PERSON WITH CEREBRAL PALSY AND SPEECH IMPAIRMENT, CANADA

What people with disabilities want:

- To be equipped with health knowledge and awareness to seek care

Why is it important:

- Delay in detection of risk or symptom leads to pursuing medical care only for emergency or acute conditions
- Links within communities to health services can encourage and better support people with disabilities to seek care

Examples of immediate action:

- Provide health education information and materials that are understandable and concrete, in accessible formats, and with images of people with disabilities.
- Reach out to people with disabilities through community health worker visits, community-based services, and collaborations between facilities and peer-led people with disabilities health groups

Examples of aspirational action:

- Offer telehealth services and smartphone-based diagnostics that are affordable, accessible and user-friendly for everyone
- Provide school-based health education programs that are disability-inclusive
- Train community health workers to use disability-inclusive screening tools and to connect people with disabilities to necessary follow-up care

2 Predictable healthcare experience

"I am always scared of what to expect, how long will he have to stay, if they have to draw blood and put holes all over his body."

CAREGIVER OF CHILD WITH DEVELOPMENTAL DISABILITIES,BRAZIL

"Google is a very great platform to know the doctor, where they sit etc. But there were no details on what he can help me with. My needs were very different – even psychiatrist won't understand me, only a person with hearing issue will understand me. The psychiatrist I went to had a website so I could connect easily with him and do a brief call with him on how he can help me."

GIRL WITH HEARING IMPAIRMENT, INDIA

What people with disabilities want:

- To be informed about what they can expect during a healthcare visit

Why is it important:

- Prior negative experiences with the health system make those who have sought care more concerned about future encounters
- An unfamiliar space may lead to a loss of control and feeling of helplessness thus reducing motivation to seek care
- Providing information about procedures and the opportunity to ask questions in advance can make a person with disabilities more confident in claiming their right to healthcare

Examples of immediate action:

- Provide Medical History Cards with relevant information on the individuals' impairment and accessibility requirements
- Install accessibility help desks or focal persons in healthcare facilities that can support patients with disabilities in seeking care

Examples of aspirational action:

- Set up services where health facilities proactively contact the patient to confirm the visit and ask them about accessibility needs
- Organize for community health workers to remind people with disabilities if they are due for upcoming appointments and provide information and support

3 Affordable health care service within reach

"The last delivery was best- there wasn't a lot of cost incurred, they didn't charge anything extra to take good care of people with disability because they had the intent to do so. You just need to be empathetic, disability doesn't require too much money, just intent. My child lost oxygen and they got an ambulance to take him to the children's hospital and didn't charge me for any fuel, etc."

WOMAN WITH VISUAL IMPAIRMENT, UGANDA

"Sometimes here when I go to the taxi - it costs me $200 to just go to half an hour distance to the hospital. I call it highway robbery. If I want to ride the bus, I don't feel safe, the ramp that comes down is so narrow – it just looks good but getting on and off is a challenge."

MAN WITH PHYSICAL IMPAIRMENT, USA

"I like both physical and online consultations, but I prefer online more because it reduces transportation charges and so much planning required for the visit. If I can take the appointment, they may come and visit me in the rural area."

WOMAN WITH EPILEPSY, KENYA

What people with disabilities want:

- To have affordable health services which are within easy reach

Why is it important:

- Economic and geographic circumstances become an obstacle to accessing healthcare

Examples of immediate action:

- Provide accessible transportation options, such as wheelchair accessible vans, and/or transport subsidies
- Leverage lessons learned from COVID-19 in providing more virtual consultations, where appropriate
- Include people with disabilities in social protection programs and/or offer health insurance or fee waivers to disability card holders

Examples of aspirational action:

- Ensure that performance-based financing programs include disability to encourage timely provision of treatment
- Explore partnerships with ride-sharing companies to offer subsidized rides for people with disabilities seeking healthcare

4 Universally designed environment

"In the radiology department, they have those adjustable tables because they are expecting people like me. But in the examination room, they don't have those tables."

YOUNG ADULT WITH PHYSICAL IMPAIRMENT, INDONESIA

"When I sat in the queue, I waited. The person called out the card- so and so come. because I couldn't hear, I didn't go when they called. I stayed until the end."

MAN WITH HEARING IMPAIRMENT, KENYA

"The space to change into the gown was really small, I couldn't shut the curtains, so I had to change looking over my shoulder. It was really embarrassing."

OLDER ADULT WITH MOBILITY IMPAIRMENT, CANADA

What people with disabilities want:

- Healthcare environments which are universally designed to accommodate people with disabilities

Why is it important:

- Inaccessible settings make it difficult or impossible for people with disabilities to seek healthcare

Examples of immediate action:

- Ensure comprehensive accessibility, including entrance, facility, toilets, equipment, for all new facilities and upgrade existing facilities, considering people with:
  - Physical impairments (e.g., ramps, accessible toilets, seating and equipment)
  - Hearing impairments (e.g., hearing loop provided, clear signage, sign language interpreter booked)
  - Visual impairments (e.g., high-contrast signage, accessible lighting, braille pavers, medical letters in different formats)
  - Psychosocial impairments (e.g., provision of calm environment and quiet spaces)
- Implement routine audits to monitor and enforce accessibility

Examples of aspirational action:

- Redesign primary health facilities to be fully accessible and climate resilient
- Leverage assistive technology into the health experience, for instance, provide intake forms that have screen reader functions when required

5 Comprehensive and mindful consultation

"I've never had direct communication with the doctor, including my own hearing doctor. Mostly they talk with my parents because they take the hearing machine and set it according to my listening power. I want to know what the doctor is saying because the problem is with me, I can't live with my parents forever."

GIRL WITH HEARING IMPAIRMENT, INDIA

"(At the health facility,) they were so accommodating – they were so open, they took my case as a special case and they were interested and treated me nicely. They also helped me make the right choice for contraceptives. The doctors were nice, they were never bothered even when I asked them hundreds of questions. I liked this better because the service providers are trained on all types of family planning – so they explain to you and take out time and help you make the right decision. In that other clinic, they were just rushing me to get the injectable."

WOMAN WITH EPILEPSY, KENYA

"Your appointment is 20 minutes, but by the time you reach there and settle in, the time is almost over. It's such a rush rush rush that you feel like you're an imposition."

OLD ADULT WITH MOBILITY IMPAIRMENT, CANADA

What people with disabilities want:

- To receive a respectful and comprehensive clinical assessment from healthcare staff providing mindful treatment and care

Why is it important:

- Patients who are treated poorly are less likely to follow through with treatment recommendations, resulting in poorer health outcomes and damaged trust in health providers

Examples of immediate action:

- Train healthcare workers on how to communicate with people with different impairments, using respectful language, knowledge on rights and accessibility for people with disabilities, and how to make appropriate referrals
- Ensure providers obtain informed consent and maintain privacy
- Ensure providers give clear decision-making support and explain next steps in treatment

Examples of aspirational action:

- Train more people with disabilities as healthcare professionals
- Ensure health records maintain detailed information about disability history and are routinely updated

6 Maintaining quality care

"For rare disabilities – there should be some support groups readily available."

GIRL WITH CHRONIC CONDITION, INDIA

"Even on drug prescriptions there is no braille, you can overdose or underdose."

WOMAN WITH VISUAL IMPAIRMENT, UGANDA

"Basic habits they should write – remove it while sleeping, bathing, when to change the battery. They should give you a prescription – what you should be doing, what you shouldn't be doing. Give me some guidance to take care of my hearing. At least it shouldn't get worse."

GIRL WITH HEARING IMPAIRMENT, INDIA

What people with disabilities want:

- To be equipped with resources and support networks to sustain care after the doctor's visit

Why is it important:

- Having clear guidance and simple pathways for follow up care allows people with disabilities to better manage their health

Examples of immediate action:

- Provide accessible documentation and information to patients about their health condition and treatment instructions to revisit at home
- Establish support groups for people with shared experiences and their caregivers
- Enable bookings for next visits while at the current visit, where appropriate
- Ensure providers communicate referral procedures and timelines clearly using methods tailored to the patient (e.g. writing down or explaining verbally)

Examples of aspirational action:

- Equip health facilities with telehealth to follow up with patients on any challenges they may face and health education tools wherever needed

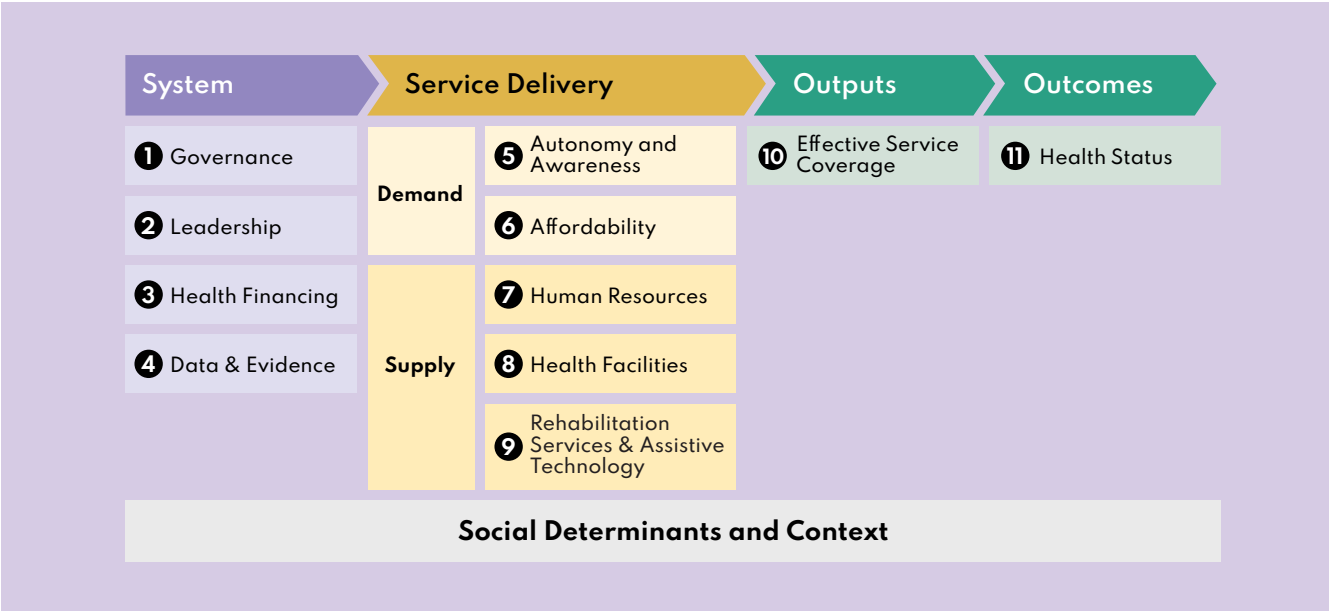
4. A framework and best practices for disability-inclusive health systems

We have introduced a vision for inclusive healthcare. The six components that support this vision reflect people with disabilities' requirements when seeking and receiving healthcare services. Health systems should be strengthened or adapted to meet this vision. In this section, a health systems framework is introduced to provide governments and global health actors with a structure to help realize inclusive healthcare for people with disabilities. Best practice examples are shared from different parts of the globe.

Introducing the Missing Billion inclusive health systems framework

A health systems framework has been developed and pilot tested by the Missing Billion Initiative. It is based upon existing conceptual frameworks and consultation with key stakeholders, including government and global health actors, bilateral stakeholders, people with disabilities, disability and health systems experts. The framework presented below aims to describe the critical components of a strong disability-inclusive healthcare system.[44,45,46] Health system indicators and national health plans can be reviewed against this framework to identify areas for strengthening disability inclusion. The social determinants of health and context are the non-medical factors and conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of life-risks and outcomes.

Missing Billion Inclusive Health Systems framework



[44] WHO EURO. 2021. Policy brief on disability-inclusive health systems.

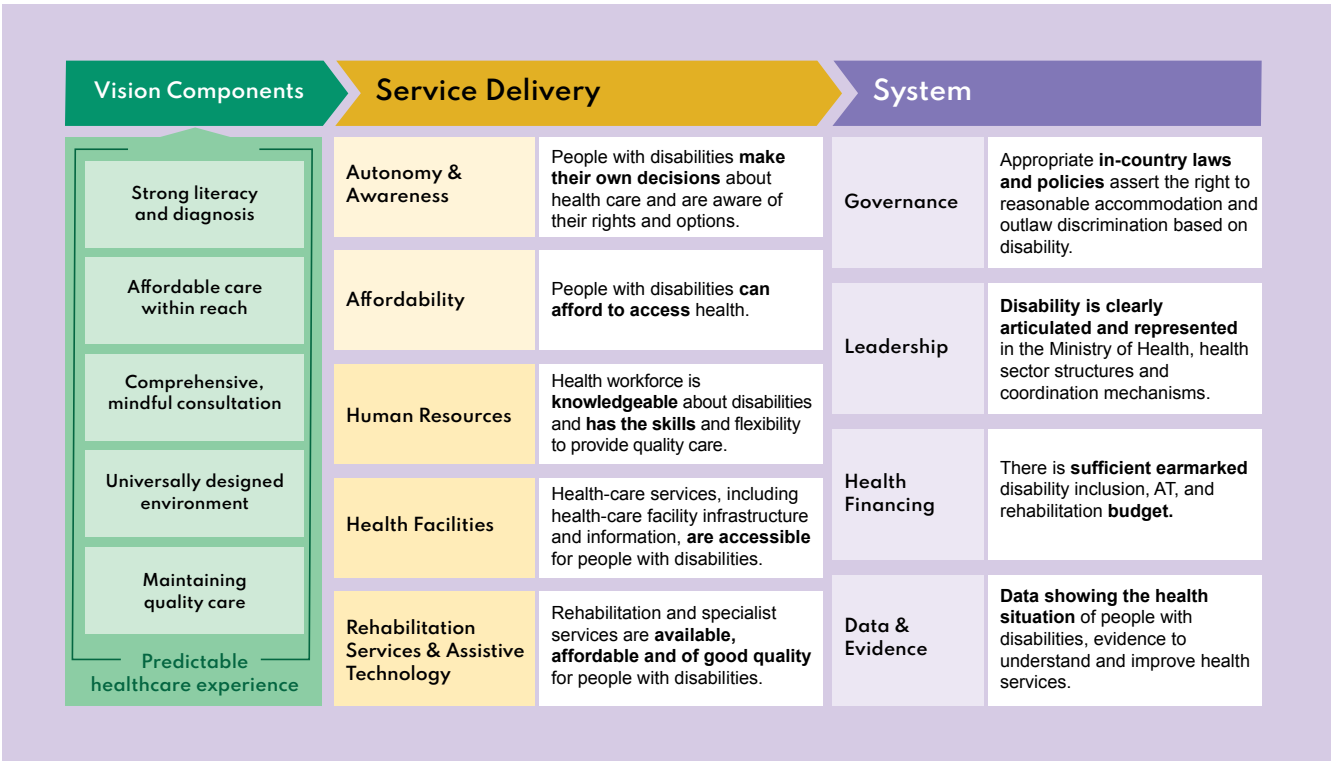
[45] WHO 6 building blocks are: 1. Service delivery; 2. Health workforce; 3. Information; 4. Medical products, vaccines and technologies; 5. Financing; 6. Leadership/governance.

[46] PHCPI Conceptual framework considers: 1. System (e.g. governance/leadership); 2. Inputs (e.g. Drugs, supplies); 3. Service delivery (e.g. Access); 4. Outputs (effective service coverage); 5. Outcomes (e.g. health status).

Translating the vision into Health Systems Objectives

We use the framework to define objectives for disability-inclusive health systems[47] that will help fulfil the vision that has been expressed by people with disabilities. For example, the vision describes that people with disabilities seek healthcare experiences that are predictable. This can only be achieved when they are aware of their rights and options (autonomy and awareness), when there is available and knowledgeable health workforce (human resources) and when health infrastructure is accessible (health facilities).

Objectives for achieving disability-inclusive health systems



The following summarizes the objectives for disability-inclusive health systems and outlines current good practices that was compiled by the Missing Billion Initiative.[47] A table providing a starting point for governments to drive action, is provided in the next section of the report.

	OBJECTIVE	EXAMPLE ACTIONS	GOOD PRACTICE EXAMPLES
Service Delivery			
Autonomy & Awareness	People with disabilities make their own decisions about healthcare and are aware of their rights and options.	Civil society and mass media campaigns raise awareness; information is available in accessible formats; patient support groups.	▸ Active Rehabilitation Services by and for people with disabilities in Poland ▸ Peer educator training on sexual and reproductive health and rights of people with disabilities in Burundi ▸ Autism and Mental Health Literacy Project (AM-HeLP) in Canada

[47] Unless referred to another source, the descriptions of the good practices can be found online: www.missingbillion.org/goodpractices

	OBJECTIVE	EXAMPLE ACTIONS	GOOD PRACTICE EXAMPLES
Affordability	People with disabilities can afford to access health services	Provision of social protection or health insurance; fee waivers for people with disabilities; integrated care and outreach programs to reduce travel costs.	▸ Accessible COVID-19 vaccination transportation in Toronto, Canada ▸ Guidance on ensuring social protection works for people with disabilities[48] ▸ International Labor Organization portal on disability-inclusive social protection[49]
Human Resources	Health-care workforce is knowledgeable about disability and has the skills and flexibility to provide quality care to people with disabilities.	Incorporate disability awareness and skills training into initial and/or ongoing healthcare curriculum; include people with disabilities in the health workforce; include disability care coordinators within teams	▸ Community Health Worker Training in India ▸ Disability-inclusive Nursing Practice Handbook in Germany ▸ Learning Disability and Autism Training for Health and Care Staff in the UK ▸ Health worker handbook on sexual and reproductive health in Ecuador ▸ Disability and inclusion training for health care workers in Tanzania ▸ Future Learn: Improving Health Assessments for People with Intellectual Disabilities ▸ Disability Training for Community Health Assistants in Zambia ▸ Guidance on approaches to improve healthcare professionals' competency on disability[50]
Health Facilities	Health-care services, including health-care facility infrastructure and information, are accessible for people with disabilities.	Establish accessibility criteria; audit facilities regularly; budget for accessibility retrofitting; design facilities and equipment for inclusion; develop incentives for accessibility.	▸ Home Testing for COVID-19 in the United Arab Emirates ▸ Sightsavers Accessibility Audit for health facilities[51]
Rehabilitation and Specialist Services	Rehabilitation (such as physiotherapy, assistive technology and medical devices) and specialist services (like ophthalmology and mental health services) are available, affordable and of good quality for people with disabilities.	Map referral pathways for rehabilitation and specialist services; increase service availability through health practice supported by mobile devices (mHealth) and task-sharing; raise awareness among healthcare workers on importance of rehabilitation and specialist services.	▸ Annual Health Checks for people with learning disabilities in the UK ▸ Wheelchair user training in El Salvador, India, Kenya, Nicaragua, and Romania ▸ Comprehensive community-based rehabilitation in Tanzania ▸ National Rehabilitation Plan in Ukraine ▸ Guidance on approaches to overcome barriers to access rehabilitation[52] ▸ Guidance on approaches to overcome barriers to access assistive technology[53] ▸ Care for Stroke – a web-based, smartphone-enabled educational intervention for management of physical disabilities following stroke[54]

[48] Disability Evidence Portal. How do we ensure that social protection assistance initiatives work for people with disabilities?

[49] International labour Organization. Disability Inclusive social protection.

[50] Disability Evidence Portal. What works to improve healthcare professionals' competency on disability?

[51] Sightsavers. Ensuring health facilities are accessible for all.

[52] Disability Evidence Portal. How can we overcome barriers to accessing rehabilitation for persons with disabilities in LMIC?

[53] Disability Evidence Portal, How can we promote access to assistive technology for individuals with disabilities in Low- and Middle-Income Settings

[54] Sureshkumar et al. 2015. Care for Stroke. BMJ Innovation

	OBJECTIVE	EXAMPLE ACTIONS	GOOD PRACTICE EXAMPLES
System Functions			
Governance	The ratification and adoption of international commitments are matched with the introduction of appropriate in-country laws, and policies that assert the right to reasonable accommodation and outlaw discrimination based on disability.	Review existing laws/policies; advocate for new or extend existing laws and/or policies; establish mechanisms to monitor implementation.	▸ National Clinical Programme for people with disability in Ireland ▸ Improving access to health care among people with disabilities in Uruguay ▸ National Roadmap for Improving the Health of People with Intellectual Disability in Australia
Leadership	Disability is clearly articulated and represented in the Ministry of Health, health sector structures and coordination mechanisms.	Establish a designated committee or focal person(s) responsible for disability-related issues in the Ministry of Health; establish coordination structures which include people with disabilities; establish leadership on disability within crisis or disaster response actions.	▸ COVID-19 Disability Advisory Group (CDAG) in Canada ▸ Advisory Committee for the COVID-19 Response for People with Disability in Australia
Health Financing	There is sufficient earmarked budget for disability inclusion, AT, and rehabilitation.	Establish budgets for the provision of disability-inclusive health services (e.g. accessibility, assistive technology); co-ordination of Ministry of Health and Ministry of Finance on inclusive health budgets; make available and provide adequate reimbursement mechanisms to account for additional costs.	▸ Dental health reimbursement for people with disabilities in Germany ▸ National Disability Insurance Scheme in Australia ▸ Coverage of disability-related services for children with disabilities in the Philippines
Data & Evidence	Data describing the health situation of people with disabilities and how their health can be improved are available, and evidence is generated to understand and improve delivery of health services.	Include measures of disability in health information systems and large-scale health surveys; undertake disability-specific surveys; undertake periodic review of health situation of people with disabilities.	▸ Learning Disabilities Mortality Review (LeDeR) programme in the UK ▸ Learning Disability Registers in the UK

5. Missing Billion road map to 2030

The Missing Billion road map to 2030 proposes a pathway to guide collective action to level up and tackle the main access barriers for people with disabilities in health. It provides guidance on the most impactful and feasible actions that can be taken by governments, health funders, and implementers.

The recommendations in this section were developed from the main findings of the report and checked with more than 10 international stakeholders (including representatives from bilateral agencies, people with disabilities, NGO experts, UN agencies, academics and experts from LMICs).

Establishing targets

People with disabilities have 2.4-fold higher mortality rates than those without disabilities and are denied 10 to 20 years of life expectancy. These gaps in life expectancy between people with and without disabilities can be closed by long-term investments in accessible, affordable, and quality healthcare. We must collaborate across multiple dimensions for disability inclusion.

Objective

Reduce the life expectancy gap of people with disabilities via disability-inclusive health systems that expect, accept, and connect people with disabilities to quality care.

Minimum targets:

THE 4 MILLION TARGETS

SERVICE DELIVERY

Autonomy	Affordability	Human Resources	Health Facilities
1 million additional people with disabilities are champions* for their right to healthcare	**1 million** additional people with disabilities in LMICs access health insurance and/ or social protection	**1 million** additional health workers trained on disabilityy	**1 million** health facilities audited and an additional 10,000 are inclusive

**Champions are defined as people who vigorously promote the right to health and support and encourage others to fulfil this right.*

To contribute to these '4 Million Targets', we urge countries to pledge for:

SYSTEM FUNCTIONS

Governance	Leadership	Health Financing	Data & Evidence
Disability-inclusive national health plans	Institutional leadership for disability-inclusive health	A health budget line for disability	Disaggregated health data by disability

We aim for stakeholders to align efforts and pledge actions over the next decade. By proposing a set of minimum targets – called the '4 Million Targets', we want to encourage governments, donors, implementing partners, and civil society to reevaluate and align their efforts and approaches and consider how the efficiency and effectiveness of their commitments and contributions can be improved. A multi-sectoral approach will be needed, including actors beyond health, such as social protection, and Ministries of Finance, and of course Organizations of Person with Disabilities. These targets were established through discussion with key stakeholders, on the basis that they are: Specific and Measurable, Achievable through collective action, Relevant to the health system framework presented and Time-Bound to be realized by 2030.

Countries are both the drivers and the beneficiaries of progress towards these targets. Governments will lead efforts to define ambitious agendas and realize objectives.

Priority actions

To achieve these targets, we are proposing priority actions that can be implemented in the short-term and deliver long-term gains. The overview of actions is not comprehensive, so stakeholders are encouraged to revise these and add to it according to context and need.

Proposed priority actions for the global health community

	OBJECTIVES	KEY GOALS	KEY ACTIONS								
			Governments	Resources required*	Priority	Donors/payors	Resources required*	Priority	Implementer (NGOs and OPDs)	Resources required*	Priority
DELIVERY	**Autonomy & Awareness**	*1 million additional. people with disabilities are champions for empowered on their right to healthcare*	▸Re-affirm rights in laws and policies	$	Top	▸Fund capacity building for OPDs to train its members on the right to healthcare	$$	Top	▸Assist OPDs with capacity building advocacy for inclusive health	$$	Top
	Affordability	*1 million additional people with disabilities in LMIC's access health insurance and/or social protection*	▸Re-affirm or expand health benefits packages and/or financing schemes	$	Top	▸Fund activities to raise awareness and increase enrollment	$$	Top	▸Assist in efforts to raise awareness and support enrollment	$$$	Top
	Human Resources for Health	*1 million additional health workers trained on disability*	▸Incorporate disability in healthcare worker training curricula (foundational and on-the-job)	$$	Medium	▸Fund training curricula development and delivery (foundational and on-the-job)	$$	Medium	▸Assist/be a service provider to governments in running pilots and trainings	$$	Medium
	Health Facilities	*1 million health facilities have been audited and an additional 10,000 are inclusive*	▸Conduct accessibility audits of clinics and upgrade facilities	$$	Medium	▸Fund development of standards for inclusive clinics ▸Fund Pilot upgrades	$	Medium	▸Develop toolkits for audits (NGOs) ▸Assist government in audits (OPDs)	$	Medium

* "$ low-cost; $$$ high-cost".

	OBJECTIVES	KEY GOALS	KEY ACTIONS								
			Governments	Resources required*	Priority	Donors/payors	Resources required*	Priority	Implementer (NGOs and OPDs)	Resources required*	Priority
SYSTEM	**Governance**	*Disability-inclusive national health plans*	▸Conduct assessments of national health sector plans	$	Top	▸Fund technical assistance of governments according to assessments	$	Top	▸Provide technical assistance to governments (NGOs)	$	Top
	Leadership	*Institutional leadership for disability-inclusive health*	▸Establish clear responsibility in Ministry of Health for disabilities	$	Top	▸Fund design and set up of leadership programs to strengthen capacity in Ministries of Health	$$	Top	▸Collaborate with leadership company/ organization to provide training (OPDs)	$$	Top
	Health Financing	*A health budget line for disability*	▸Negotiate with Ministries of Health & Finance counterparts and set budget line	$	Long-term	▸Include budget line in all donor funding projects on disability ▸Fund costing analysis and investment case for systems improvements	$ $$	Top	▸Provide technical assistance to governments (NGOs) ▸Advocate with governments on the importance of data	$ $$	Top
	Data & Evidence	*Disaggregated health data by disability*	▸Include disability disaggregation in national health surveys, analyze data and set targets for inclusion	$	Top	▸Fund technical assistance and analytical capacity for government-owned surveys, and dorm global database on all existing data	$$	Top	▸Run surveys ▸Advocate with governments on the importance of data	$$	Top

* "$ low-cost; $$$ high-cost".

Measuring impact

Generating more data on the health, disaggregated by disability, while also using existing data more effectively is a priority so that we can count what matters and track progress. Opportunities include:

- **Analyze existing data:** In June 2022, the Global Health Data Exchange included 2,491 datasets with both health and disability indicators. This data is mostly un-analyzed with respect to disability and health and so a priority is to use this existing information.
- **•Conduct more disability-specific surveys** to generate an in-depth understanding of the experiences of people with disabilities in terms of healthcare needs and coverage.
- **Include disability in routine health and demographic surveys,** such as MICS and Demographic and Household Surveys to generate large-scale comparable data.
- **Include disability indicators in medical records** to allow disaggregation. For instance, in Australia, France and Korea disability is measured in national health insurance programs and in the UK there is a Learning Disability Register linked to general practitioner records.
- **Undertake systematic reviews** of interventions to improve healthcare access for people with disabilities. Evidence and Gap Maps can show where sufficient data is available to allow a review.[55]

[55] Saran et al. 2020. Evidence and gap map of studies assessing the effectiveness of interventions for people with disabilities in low- and middle-income countries. Campbell Collaboration.

Activating a global movement

More needs to be done and can be done within the health system to reach people with disabilities and close the sizeable mortality gap and other disparities. Without action to tackle barriers for the one billion people affected, SDG 3 and other health targets will not be realized. The authors of this report, along with members of the Advisory Panel, call all stakeholders to initiate and collaborate on the following to strengthen the implementation of disability-inclusive health systems.

In the words of Dr. Tedros Adhanom Ghebreyesus, Director General, World Health Organization:

"Including the experiences and skills of people living with disabilities in the design and delivery of health systems is fundamental to achieving Health For All".[56] The first Missing Billion report described the widespread exclusion of people with disabilities from health systems, and how this led to worse health outcomes. Based on new data and systematic reviews, this report underlines how this exclusion makes it impossible to reach the SDGs, UHC and other health targets, or fulfil the right to healthcare of people with disabilities.

We have worked with people with disabilities to reimagine a health system where people with disabilities are expected, accepted, and connected, and the steps needed to achieve this vision.

Now is the time for us to come together as a global movement and pledge to improve access to healthcare for people with disabilities, and thereby achieve health for all.

To all stakeholders:	1 Pledge to actions to close the mortality gap and to reimagine the health system for people with disabilities.
	2 Raise awareness and advocate for systems that expect, accept and connect people with disabilities to quality care, both individually and through a global mobilization campaign.
	3 Establish a consortium of global health actors committed to disability inclusion who work together towards a common goal. The '4 Million Targets' and the priority actions suggested in this report can be the starting point for that collaboration.
To governments and implementers:	4 Measure and improve the level of disability inclusion in the health system (e.g., against the Missing Billion inclusive health systems framework).
	5 Engage people with disabilities throughout policy development, service planning and delivery.
To funders:	6 Adjust health investments to be disability-inclusive with specified budget lines and accountability systems for monitoring progress.[57] a. Mainstream disability - incorporate disability inclusion as a prerequisite condition throughout the full portfolio of health investments via bilateral, multilateral and partner engagement. b. Disability-focused investments – to meet the additional healthcare needs of people with disabilities.
To researchers and innovators:	7 Generate and analyze high quality data on healthcare needs of people with disabilities, potentially combined as a global reporting system with an annual report.
	8 Co-design solutions and innovate where gaps exist.

[56] Dr. Tedros [@drtedros]. 2022, January 4. Twitter.

[57] Guidance on disability-inclusive planning and budgeting is provided by CBM, 2012, Inclusion made easy.

6. Appendices

6.1. Life Expectancy scoping table

Study	Impairment type	Location	Population	Average life expectancy gap
Bahk J, Kang HY, Khang YH., The Life Expectancy Gap between Registered Disabled and Non-Disabled People in Korea from 2004 to 2017.	Any functional impairment	Korea	all	16-20 years
Zheng XY, Chen SJ., Life expectancy of people with physical disabilities in China.	Any functional impairment	China	all	13-17 years
Tareque MI, Chan A, Saito Y, Ma S, & Malhotra R., The Impact of Self-Reported Vision and Hearing Impairment on Health Expectancy.	Hearing and vision impairment	Singapore	60+	4 years
Heslop, P. et al., The Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities in the UK: A Population-based Study.	Intellectual disability	UK	5-75	13-20 years
Walker et al., Mortality in Mental Disorders and Global Disease Burden Implications: A Systematic Review and Meta-analysis.	Mental disorders	Global	-	10 years
Hjorthøj C, Stürup AE, McGrath JJ, Nordentoft M, Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis.	Schizophrenia	Global	all	20-27 years
Hughes-McCormack, L., et. Al., Birth incidence, deaths and hospitalisations of children and young people with Down syndrome, 1990–2015: birth cohort study.	Down syndrome	Global	all	28 years
Hagen EM, Lie SA, Rekand T, Gilhus NE, Gronning M, Mortality after traumatic spinal cord injury: 50 years of follow-up.	Spinal cord injury	Norway	all	7 years
Fekadu, A. et. al., Excess mortality in severe mental illness: 10-year population-based cohort study in rural Ethiopia.	Severe mental illness	Ethiopia	18+	28 years

6.2. Data tables from UNICEF Multiple Indicator Cluster Surveys (MICS) analysis[58]

Definitions: The adjusted prevalence ratio (aPR) is the ratio of prevalence of the outcome in those with a disability to the prevalence without a disability, adjusting for age. The 95% confidence interval (95% CI) is a range of values that you can be 95% confident contains the true mean of the population.

The current list of 37 countries in the MICS dataset is: Algeria, Argentina, Bangladesh, 'Belarus', Central African Republic, Chad, Costa Rica, Cuba, Democratic Republic of Congo, Georgia, Ghana, Guinea-Bissau, Guyana, Iraq, Kiribati, Kosovo, Kyrgyzstan, Lao, Lesotho, Madagascar, Malawi, Mongolia, Montenegro, North Macedonia, Nepal, State of Palestine, Serbia, Sierra Leone, Sao Tome and Principe, Suriname, Thailand, The Gambia, Togo, Tonga, Tunisia, Turkmenistan, Zimbabwe.

Regions: East Asia and Pacific (EAP), Europe & Central Asia (ECA), Latin America and the Caribbean (LAC), Middle East and North Africa (MENA), South Asia (SA), Sub-Saharan Africa (SSA).

Child health indicators	All children			Regional estimates					
	% disabled	% non-disabled	aPR (95% CI)	EAP	ECA	LAC	MENA	SA	SSA
Health status/development									
Acute respiratory infection in past two weeks	34%	27%	1.2 (1.1-1.4)	1.3 (0.9-1.8)	1.0 (0.5-2.3)	1.5 (1.1-2.0)	1.3 (1.1-1.6)	1.2 (0.8-1.7)	1.2 (1.1-1.3)
Diarrhoea in past two weeks	18%	13%	1.4 (1.1-1.7)	1.6 (0.9-2.9)	1.8 (0.6-5.5)	1.6 (0.9-3.0)	1.9 (1.2-2.9)	1.7 (1.0-3.0)	1.3 (1.1-1.4)
Fever in past two weeks	28%	23%	1.2 (1.0-1.5)	1.4 (0.9-2.1)	0.7 (0.2-3.1)	1.2 (0.8-1.9)	1.5 (1.0-2.1)	1.2 (0.8-1.9)	1.2 (1.1-1.3)
Early Child Development index	38%	56%	0.7 (0.6-0.7)	0.7 (0.5-0.9)	0.7 (0.6-0.7)	0.7 (0.5-0.9)	0.5 (0.4-0.7)	0.5 (0.4-0.8)	0.7 (0.6-0.8)
Wasted	8%	5%	1.4 (1.0-2.2)	2.4 (1.0-5.8)	2.9 (0.3-27.6)	1.7 (0.5-5.5)	2.7 (0.9-7.6)	1.5 (0.8-2.7)	1.3 (1.0-1.7)
Stunted	39%	32%	1.2 (1.0-1.4)	1.6 (1.2-2.1)	1.7 (0.5-6.0)	1.5 (1.1-2.1)	1.6 (1.0-2.5)	1.4 (1.2-1.8)	1.1 (1.0-1.2)
Overweight	5%	5%	1.0 (0.7-1.7)	0.9 (0.4-1.9)	0.7 (0.1-6.9)	0.8 (0.4-1.5)	1.0 (0.6-1.7)	1.1 (0.3-4.2)	1.2 (0.9-1.6)
Preventative									
Ever breastfed (age 2)	87%	85%	1.0 (1.0-1.1)	1.0 (1.0-1.1)	1.0 (1.0-1.1)	1.0 (0.9-1.1)	1.0 (0.9-1.1)	1.0 (0.9-1.1)	1.0 (1.0-1.0)
Population under 5 that slept under a bednet	85%	83%	1.0 (1.0-1.1)	1.0 (0.9-1.2)	-	-	-	-	1.0 (1.0-1.0)
Treatment									
Sought care for acute respiratory infection	55%	51%	1.1 (1.0-1.2)	1.1 (1.0-1.3)	1.6 (1.2-2.0)	1.2 (1.0-1.3)	1.0 (0.8-1.1)	0.9 (0.7-1.2)	1.0 (0.9-1.1)
Sought care for diarrhoea	57%	52%	1.1 (0.9-1.3)	1.2 (0.9-1.5)	0.6 (0.1-5.0)	1.3 (1.0-1.7)	1.0 (0.7-1.5)	1.0 (0.7-1.5)	1.1 (1.0-1.2)
Sought care for fever	57%	52%	1.1 (1.0-1.2)	1.2 (1.0-1.4)	1.2 (0.7-1.9)	1.2 (1.0-1.3)	1.1 (0.9-1.3)	0.9 (0.7-1.2)	1.0 (1.0-1.2)
Received any oral rehydration salts	33%	29%	1.1 (0.9-1.4)	1.4 (1.0-2.0)	2.9 (1.0-8.3)	1.2 (0.7-2.0)	1.0 (0.4-2.4)	1.0 (0.8-1.3)	1.1 (0.9-1.3)
Treatment with ACT among children who receive anti-malarials	7%	7%	0.9 (0.4-2.2)	2.6 (0.2-35.1)	-	-	-	-	0.9 (0.6-1.3)

[58] https://mics.unicef.org/

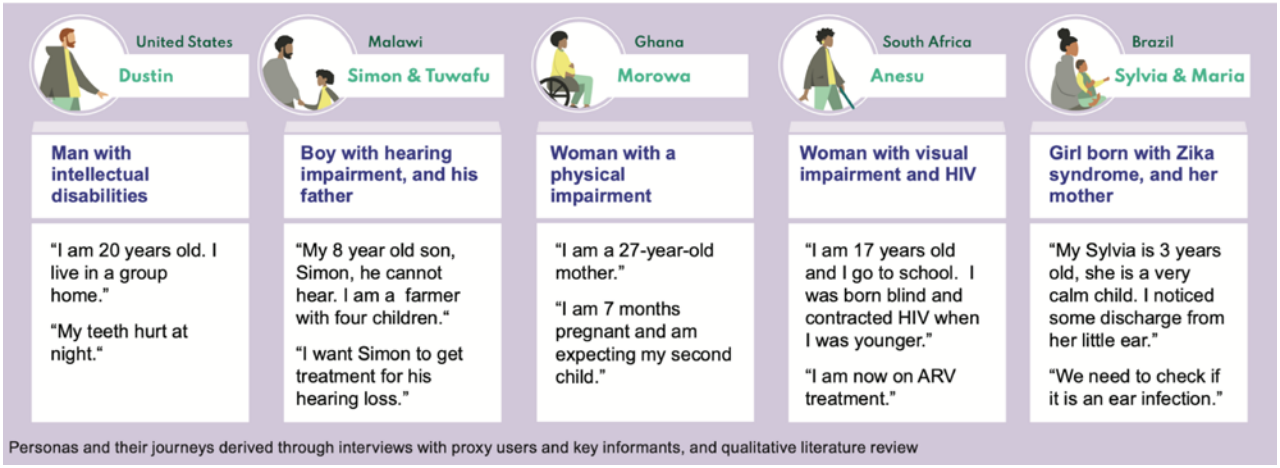
Maternal and reproductive health indicators	All women			Regional estimates					
	% disabled	% non-disabled	aPR (95% CI)	EAP	ECA	LAC	MENA	SA	SSA
HIV									
Counselling during ANC	39%	38%	1.0 (0.8-1.4)	-	0.9 (0.4-1.8)	1.0 (0.8-1.2)	1.0 (0.1-6.6)	1.5 (0.3-7.3)	1.0 (0.9-1.3)
Testing during ANC	54%	54%	1.0 (0.9-1.2)	1.2 (0.7-1.9)	1.1 (0.6-1.8)	1.0 (0.9-1.1)	0.5 (0.1-2.2)	0.7 (0.1-6.8)	1.0 (0.9-1.2)
Malaria*									
3+ doses of IPT for malaria in pregnancy	23%	15%	1.5 (0.6-3.8)	-	-	-	-	-	1.5 (0.6-3.8)
Percent of pregnant women who slept under bednet	90%	90%	1.0 (1.0-1.0)	-	-	-	-	-	1.0 (1.0-1.0)
Family Planning									
Contraceptive coverage for women married/in union	44%	48%	0.9 (0.8- 1.0)	1.0 (0.7-1.3)	1.0 (0.7-1.2)	1.0 (0.9-1.1)	1.0 (0.9-1.1)	0.8 (0.8-0.9)	0.9 (0.7-1.2)
Maternal Health									
4 or more ANC visits	74%	74%	1.0 (1.0 -1.0)	1.1 (1.0-1.2)	1.0 (1.0 -1.0)	1.0 (1.0 -1.0)	1.0 (0.9 -1.1)	1.0 (0.7-1.4)	1.1 (1.0-1.3)
Institutional delivery	86%	85%	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (0.8-1.3)	1.1 (1.0-1.2)
Qualified ANC provider	95%	95%	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (0.9-1.1)	1.0 (1.0-1.0)
Skilled birth attendant	80%	80%	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (0.7-1.3)	1.1 (1.0-1.2)

* data available for 13 countries: Central African Republic, Chad, Democratic Republic of Congo, Ghana, Guinea-Bissau, Guyana, Lao, Madagascar, Malawi, Sao Tome et Principe, Sierra Leone, Togo, and Zimbabwe

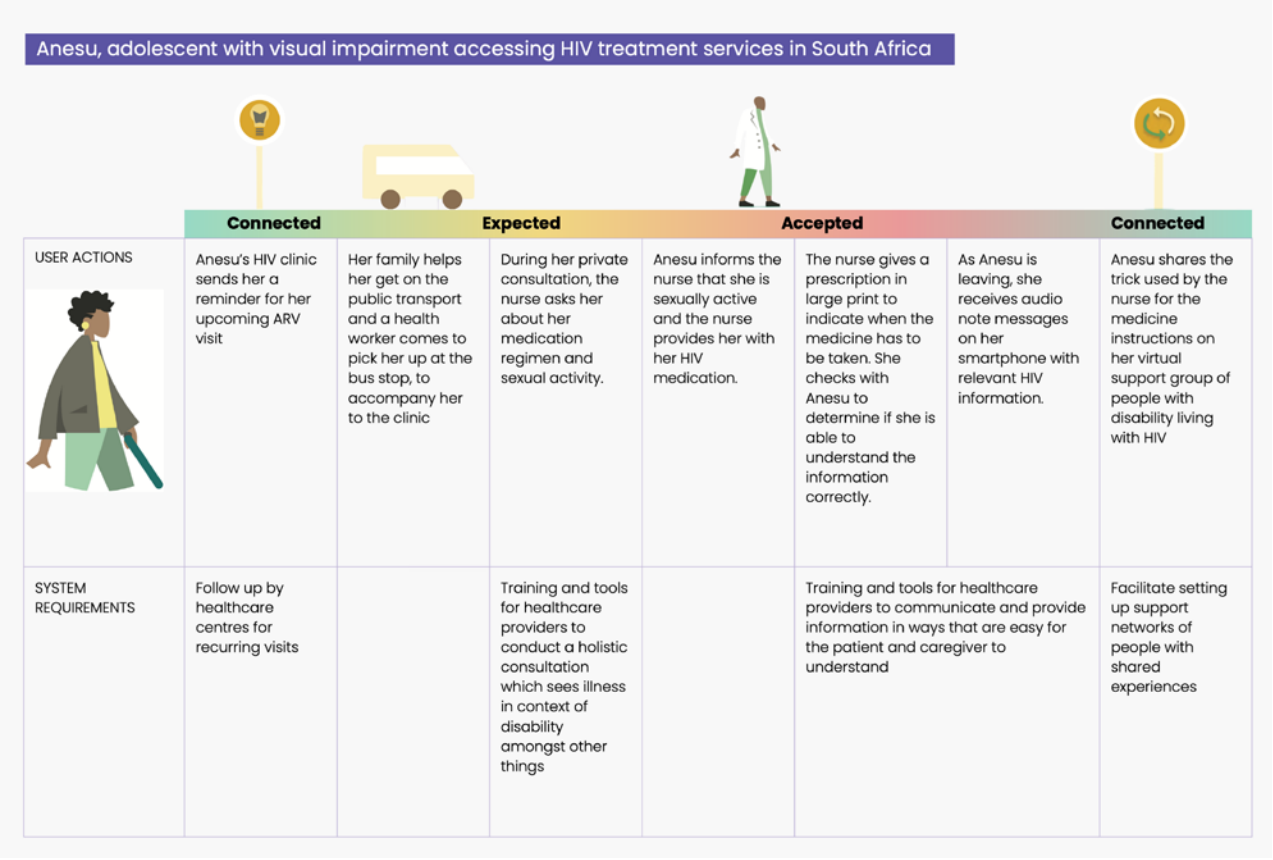
Population health indicators	All adults			Regional estimates					
	% disabled	% non-disabled	aPR (95% CI)	EAP	ECA	LAC	MENA	SA	SSA
HIV testing and knowledge (adults)									
Comprehensive knowledge about HIV prevention	21%	28%	0.7 (0.6-0.9)	1.6 (0.5-5.9)	0.7 (0.5-1.0)	0.8 (0.5-1.0)	0.8 (0.5-1.1)	0.7 (0.4-1.0)	0.7 (0.6-0.9)
Knowledge of mother-to-child transmission	37%	38%	1.0 (0.8-1.1)	1.1 (0.8-1.5)	1.0 (0.8-1.3)	0.9 (0.8-1.1)	1.0 (0.8-1.2)	1.1 (0.7-1.6)	0.9 (0.8-1.1)
Tested in the past 12 months	14%	13%	1.0 (0.8-1.3)	0.8 (0.5-1.1)	1.2 (0.8-1.8)	1.1 (0.9-1.3)	0.9 (0.4-1.9)	1.1 (0.2-7.0)	1.0 (0.8-1.2)
Ever tested	41%	43%	1.0 (0.9-1.0)	0.9 (0.8-1.1)	0.9 (0.8-1.1)	1.0 (0.9-1.0)	1.0 (0.7-1.4)	0.9 (0.4-1.7)	0.9 (0.9-1.0)
Sexually active young people (15-24) who have been tested for HIV and know the result	54%	49%	1.1 (0.8-1.5)	0.7 (0.2-2.5)	1.3 (0.6-2.7)	1.2 (0.9-1.6)	0.8 (0.2-4.1)	0.5 (0.01-25.4)	1.1 (0.9-1.3)
Health insurance (all ages)									
Health insurance coverage (18-49)	12%	11%	1.0 (1.0-1.1)	0.9 (0.6-1.4)	1.0 (0.9-1.0)	0.9 (0.8-1.1)	1.0 (0.9-1.1)	1.3 (0.3-5.2)	0.7 (0.5-1.0)
Health insurance coverage (5-17)	19%	21%	0.9 (0.9-1.0)	0.9 (0.7-1.2)	1.1 (0.8-1.7)	0.9 (0.9-1.0)	0.9 (0.9-1.0)	1.2 (0.7-2.1)	0.9 (0.8-1.0)
Health insurance coverage (2-4)	12%	11%	1.0 (1.0-1.1)	0.8 (0.6-1.1)	1.0 (1.0-1.1)	1.1 (0.9-1.2)	0.9 (0.7-1.1)	0.8 (0.1-13.9)	0.9 (0.8-1.1)
Malaria (all ages)*									
Population slept under a bednet (all ages)	68%	70%	1.0 (0.9-1.0)	1.1 (0.9-1.3)	–	0.9 (0.6-1.3)	–	–	1.0 (0.9-1.0)

* data available for 13 countries: Central African Republic, Chad, Democratic Republic of Congo, Ghana, Guinea-Bissau, Guyana, Lao, Madagascar, Malawi, Sao Tome et Principe, Sierra Leone, Togo, and Zimbabwe

6.3. Detailed User Journeys demonstrating the vision for inclusive health system.



Personas and their journeys derived through interviews with proxy users and key informants, and qualitative literature review



Dustin, man with intellectual disabilities accessing dental care services in USA

	Connected	Expected		Accepted			Connected
USER ACTIONS 	Dustin notices some decay while checking his teeth in the mirror post brushing. He recognises early signs of tooth decay from his lessons on recognising early indicators, conducted at the group home.	Dustin alerts his caregiver. The caregiver at the group home books an appointment for Dustin at the dental clinic. Dustin gets an extra long appointment so that he doesn't feel rushed	The driver from the group home takes him to the dental clinic where he is directly taken to the dentist	The dentist looks at Dustin's medical history, asks questions about his pain in simple language and checks his mouth. Dustin is able to comply with the dentist because he has been taught about going to the dentist	Since Dustin had detected the problem at an early stage, the dentist performs a basic procedure which Dustin is able to cover with his disability pension	The dentist makes simple notes for Dustin to follow up on necessary care at the group home, and provides Justin with a special toothpaste to use while brushing.	The health staff follows up with Justin in some days to check if the pain in his teeth has reduced
SYSTEM REQUIREMENTS	Development of accessible and simple health information to monitor subtle, early indicators of illness	A standard operating procedure for healthcare visits available in simple language	Registration of people with disability in a central database along with their medical records, allowing for benefits such as post-hours checkups and disability pension			Training and tools for healthcare providers to communicate and provide information in ways that are easy for the patient to understand	Follow up and remote consultations post healthcare visits

Morowa, woman with physical impairment accessing maternal health services in Ghana

	Connected	Expected		Accepted			Connected
USER ACTIONS 	The community health worker reaches out to Morowa to check if she has been going for the antenatal checkups. Morowa explains that although she wants to attend, she can't paddle her wheelchair to the health centre as it is too far and the public bus isn't accessible.	The community health worker arranges for an accessible ambulance to pick up and drop Morowa for ANC visits and also for the delivery.	The hospital has a ramp for her wheelchair and the wards are wide enough for her to go through.	The nurses bring the adjustable delivery bed down to Morowa's level and assist her in getting on the bed.	After the delivery, the doctor recommends exercise that aligns with her abilities.	The doctor also provides her contact details of centres/providers close to her area who can conduct home visits to help with the postnatal care.	Upon reaching home, Morowa receives the doctor's advice on her mobile phone along with a link to a virtual global support group of new mothers with mobility impairments. Morowa is excited to learn from others' experience and provide the best care for her child.
SYSTEM REQUIREMENTS	Monitoring information on who is able to access healthcare and who isn't as well as difference in frequency of recurring visits CHW has list of people with disabilities in the community	Creating a concrete response to improve outcomes and prevent dropout for those who are unable to access healthcare	Information on healthcare accessibility requirements for a broad range of disabilities for planning. Accessibility requirements consider design, construction, and operation of buildings and facilities, products and equipment, and transportation vehicles.		Medical education and research expands to include healthcare scenarios for people with disability	Target efforts on improving access for geographically remote homes. Developing home environments conducive to providing care.	Follow up and remote consultations post healthcare visits and referrals to other care and support networks

Simon & Tuwafu, boy with hearing impairment, and his father seeking specialized hearing services in Malawi

	Connected	Expected			Accepted			Connected
USER ACTIONS 	Tuwafu notices that Simon only hears them when he looks at them. The school alerts Tuwafu that Simon is not able to follow in class and it may be a sign of hearing loss	The school advise Tuwafu to connect with the frontline health worker and share the problem. The health worker does some basic screening tests and explains the results in simple language.	The health worker connects Tuwafu to a specialized hospital in Blantyre and schedules an appointment. She gives them an information handout to help them understand what the visit would be like.	Since the hospital is 100 kms away, the health worker books a van for Simon & Tuwafu to reach the hospital. Once at the hospital, the doctor calls Simon & Tuwafu in at the scheduled time.	The doctor is very patient and friendly with Simon. He conducts a detailed hearing test for Simon along with some additional tests to rule out any other conditions	The doctor suggests and provides a hearing aid for Simon. Considering the situation of the family, the hospital connects them to an NGO to cover the costs of the service and provide support with early intervention. The staff helps create a Disability Identification Card for Simon.	The doctor makes simple notes for Tuwafu to understand the basic functioning of the hearing aid along with some concrete actionables for early intervention.	The health staff follows up with Tuwafu in some days to check if the hearing aid is working fine.
SYSTEM REQUIREMENTS	Development of accessible and simple health information to monitor subtle, early indicators of illness	Development of simple tools to help frontline health workers screen and identify disabilities.	A standard operating procedure for healthcare visits available in accessible forms	Transport arranged by healthcare service	Training and tools for healthcare providers to communicate and provide information in ways that are easy for the patient to understand	Remittances and subsidies to help afford quality healthcare. Registration of people with disability in a central database along with their medical records. Facilitate connecting people with disabilities to support networks		Follow up and remote consultations post healthcare visits

Sylvia & Maria, a girl born with Zika and her mother, accessing health services for an ear infection in Brazil

	Connected	Expected		Accepted		Connected
USER ACTIONS 	Maria notices a change in Sylvia's behaviour, that she's irritable and crying a lot. She notices a discharge coming out of Sylvia's ear.	Maria searches for a nearby ear clinic and scans through its information handout to understand what the visit would be like and the accommodations in place.	Maria & Sylvia reach the clinic using the bus. They are able to get a walk-in appointment without waiting a lot.	The doctor is very calm and friendly with Sylvia. She conducts a detailed ear examination for Sylvia along with some additional tests to rule out any other conditions. She writes down the medication.	The doctor gives some notes to Maria on preventing ear infection and managing at home	Sylvia feels much better after taking the medication. The health staff follows up with Maria in some days to check if Sylvia's ear infection is better.
SYSTEM REQUIREMENTS		A standard operating procedure and accommodations for healthcare visits available in simple language		Training of health workers, i.e. primary healthcare workers, about disabilities		Follow up and remote consultations post healthcare visits

MISSING BILLION