MISSING BILLION

Missing Billion Toolkit – System Level Assessment

October 2023

Contents

Acknowledgements

This system level assessment was developed with the support and insights of many contributors. We would like to thank:

- Research partners in Brazil, Maldives and Zimbabwe who tested the feasibility of the indicators
- Participants in the design process including government and non-governmental organization representatives from Bangladesh, India, Indonesia, Malawi, Nigeria, South Africa
- Disability and inclusion experts, Shilpa Das and Jacques Lloyd
- Expert committee members who provided overall feedback and expertise
- London School of Hygiene and Tropical Medicine
- Scope Impact
- Mckinsey Health Institute

MISSING BILLION

Introduction

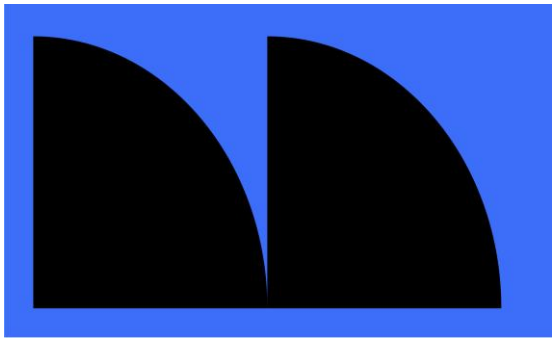
Background

- **People with disabilities include those who have 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.
- **The Missing Billion reports from 2019 and 2022 highlight that people with disabilities experience worse health than others in the population**, across the Sustainable Development Goal 3 targets.
- People with disabilities face significant barriers to access to healthcare and suffer from worse health outcomes on multiple dimensions. **For example, their mortality rates are 2.4x higher, they are 3x more likely to have diabetes, and 2x more likely to have HIV/AIDS**
- **Globally, there are at least 1.3 billion people with disabilities, making up 16% of the population**. Failure to ensure the right to healthcare of people with disabilities will therefore mean that global targets, such as Universal Health Coverage, will be difficult or impossible to achieve.

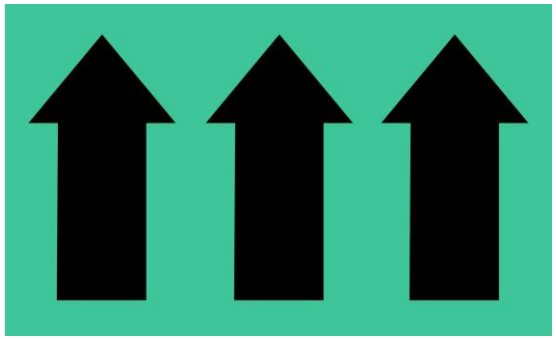
The Missing Billion Toolkit – System Level Assessment

- **The Missing Billion Initiative has thus developed an assessment (the System Level Assessment or SLA) – the first assessment in its toolkit– to evaluate the extent of disability inclusion in the health system**. The main purpose of the tool is to allow Ministries of Health to assess their health system and identify where changes are needed.
- **The SLA includes a set of indicators, steps and tools** to support actors to identify where there is progress and where gaps remain in order to spark action.
- **Repeated use will enable monitoring of trends over time and may also enable assessment of the impact of specific interventions.** Consistent use of the tool globally can highlight areas of good practice that could be implemented in other settings.
- **The tool was designed to support Ministries of Health but might also be used by disability rights groups use it to identify gaps and advocate for change**, researchers, and as part of monitoring in disability inclusion programs.

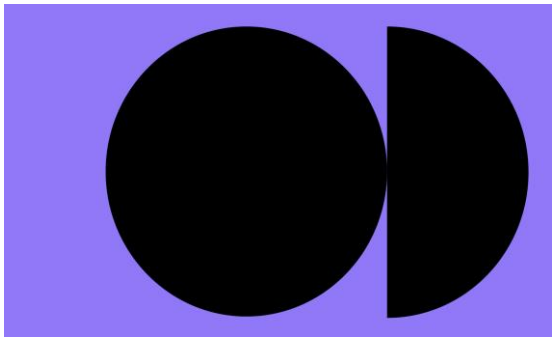
Objectives of the System Level Assessment



Collate data about the health system in order to set a benchmark for disability inclusion in the health sector.



Identify the ways in which the health system could be more inclusive of people with disabilities.



Continue to monitor progress over time using the indicators.

Development of the SLA

The team at the Missing Billion Initiative developed a draft of the SLA framework and the indicators inspired by the work of PHCPI and Levesque's framework on patient-centered access to healthcare. The framework was then tested with research partners in Brazil, Maldives and Zimbabwe, and amended subsequently.

A design process to develop the steps and tools was then led by Scope Impact. It included a validation workshop with an expert committee, followed by remote individual sessions with representatives from Ministries of Health and their technical partners. Two rounds of consultations were held to understand use cases for the SLA and suggestions for how to conduct the assessment, including advocacy, financial considerations, potential users of the SLA, and ways to use the toolkit. Several experts in disability inclusion, including persons with disabilities, served as advisors throughout the process.

Since then the SLA has been deployed in a number of settings and countries. Part of this first phase of application was piloting a contextually-adjusted SLA in a Middle Eastern country in close collaboration with the local Department of Health.

Development of the SLA v.2

2020	2021	2022	2023
Initial development	**Pilot-testing**	**Process design and tool**	**Further revisions**
• Development of v.1 framework and indicators, building on the work of PHCPI and Levesque's framework on patient-centered access to healthcare.	• Pilot-testing of v.1 framework and indicators with research partners in Brazil, Maldives and Zimbabwe.	• Definition of application process and tools. • Consultations with expert committee. • Individual sessions with representatives from ministries of health and their technical partners.	• Application of v.1 in Uganda, Chile, South Africa • v.2 complete after rounds of application and iteration on the v.1 assessment • On-the-ground application of v.2 in the Middle East

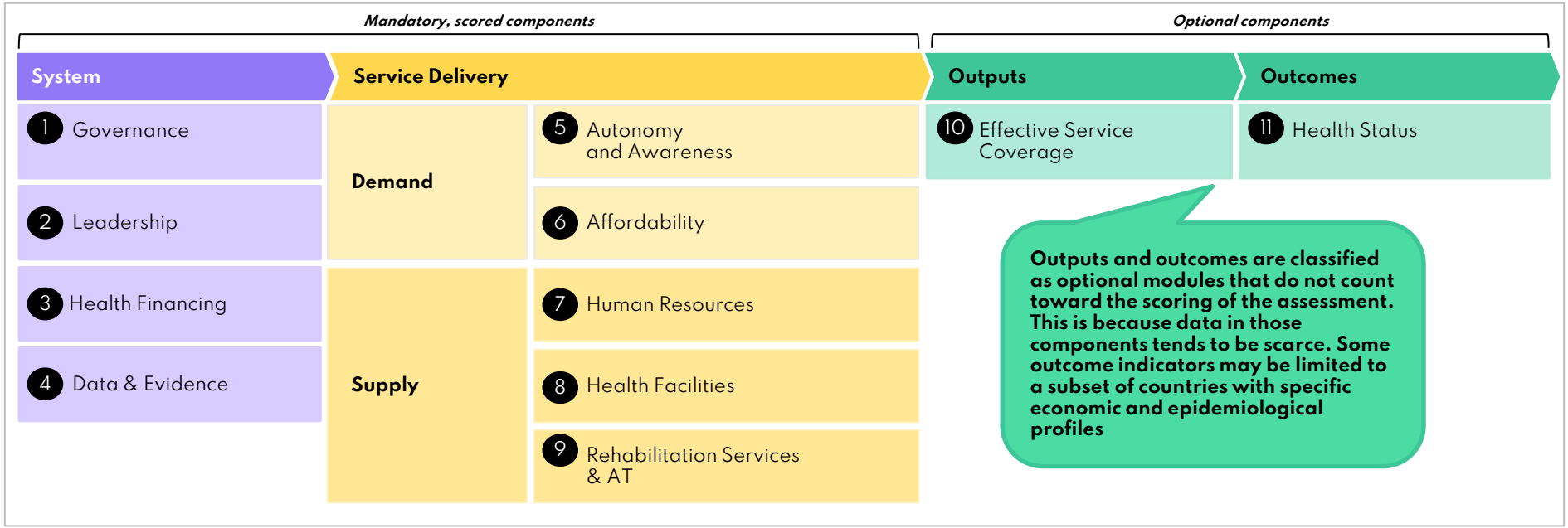
MISSING BILLION

Missing Billion Health Systems Framework

The SLA and its indicators were developed based on the health system framework. The framework identifies key leverage points in the health system for moving towards greater disability inclusion. It also includes expected changes in outcomes and health status to monitor whether health system improvements are having the intended impact.

The MB SLA has mandatory and optional SLAs

Missing Billion Inclusive Health Systems Framework



How the SLA is scored

System level assessment is comprised of 4 categories and 11 components and 34 indicators

Category	# of components	Weight
System	4	44.44%
Service delivery	5	56.56%
Output	1	NA
Outcomes	1	NA

Weighting is equally distributed between 9 components of system and service delivery (each at 11.11%)

For assessment of the system, **system and service delivery categories will only be considered** since these two components will be the founding pillars for output and outcome categories, **making the weight equally distributed between 9 components of system and service delivery (each at 11.11%)**

Output and Outcome categories are optional because data tends to be scarce and only applicable to a subset of countries with a specific socioeconomic profile

However, scoring is only based on system and service delivery categories

Category	Components	# of indicators
System	Governance	5
	Leadership	4
	Health financing	3
	Data and Evidence	7
Service delivery	Autonomy& awareness	3
	Affordability	4
	Human resources	3
	Health facilities	2
	Assistive technology	3

Each indicator will have a maximum score of 1, with different formats to getting a full score depending on the indicator's metric[1]

The **average score of indicators forms the score of each of the nine scored components**.

The scores of each of the nine components is then averaged with equal weights across to calculate the overall score for the System Level Assessment

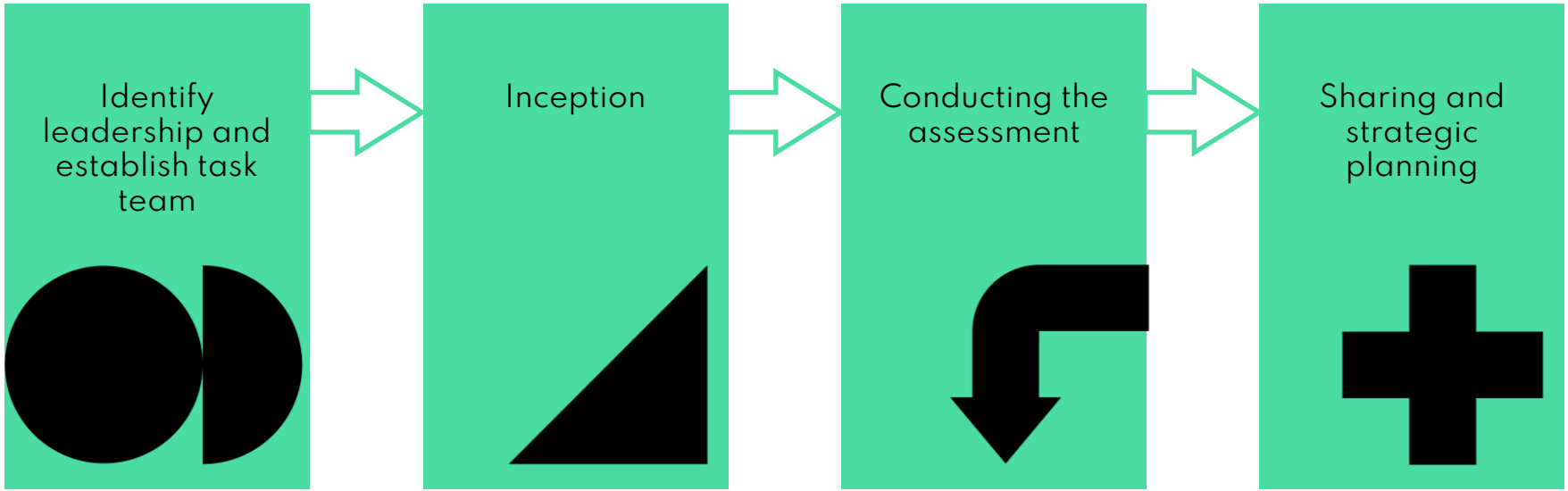
1. Example: Yes/No metrics will have a scoring 1/0, while metrics that have more detailed criteria will have an incremental scoring with each criteria that is met, scoring logic for each indicator is added to SLA

MISSING BILLION

SLA timelines

The **overall process** of conducting the SLA **should take about two to three months**, however, will vary from case to case. The indicator set has been developed to be drawn from existing sources to help keep the process streamlined. In case the SLA is initiated by entities other than the MOH, the process may be extended due to additional alignment needed

Missing Billion SLA Process



Who should lead the assessment process?

ASSESSMENT LEAD

Ideally the disability focal point or disability inclusion unit in the Ministry of Health (MOH) will lead the process. If such a unit does not exist, then it may be led by the unit responsible for primary care, equity or vulnerable populations for example.

The lead will establish a task team and consult with other stakeholders throughout the process.

The process could also be led by and NGO or an OPD in coordination with the MOH.

MEANINGFUL PARTICIPATION OF PERSONS WITH DISABILITIES

Throughout the SLA, it will be important to ensure the active involvement of people with disabilities in the planning, decision-making and monitoring related to the assessment.

As people with disabilities are actively involved, **ensure that all processes/activities are inclusive and accessible** (e.g., hire a sign language interpreter, if necessary, ask task team members to speak slowly)

TASK TEAM

A task team should be established, led by the assessment lead. Teams are typically composed of 5-7 members but could be larger depending on stakeholder involvement needed.

The team should **include representatives from** relevant departments in the **Ministry of Health, persons with disabilities and organizations of persons with disabilities, technical and NGO partners and donor representatives.**

MISSING BILLION

Inception

The **task team should organize a kick-off meeting** where key facts about disability and health are shared and the team develops a terms of reference to be clear about how they will work together over the course of the assessment.

Suggested activities for task team 1/2

MAP KEY STAKEHOLDERS:

Identify organizations and influential people who should be involved in and/or informed about the SLA and at what points in the process they should engaged.

MOBILIZE SUPPORT:

Meet with key decision makers and financial partners to sensitize them about the need for disability inclusion in the health sector **and to mobilize the political will and financial support needed** to conduct the assessment and implement recommendations from the assessment findings.

Suggested activities for task team 2/2

SENSITIZATION MEETING/INCEPTION WORKSHOP:

Organize a meeting or workshop with a broader array of stakeholders to begin sensitizing them to disability inclusion in the health sector and engage them in the process. Earlier engagement may assist with ensuring their participation and support in planning and implementing actions based on findings from the assessment. The meeting might take two possible forms:

- a **brief one-to-two-hour event** with sensitization activities and information sharing
- a **half-day workshop** that involves stakeholders in some of the planning for the assessment, such as identifying data sources and other stakeholders to involve.

You should **provide time for a person with disabilities or a caregiver to share their experience**

Potential discussion points during workshop:

- Basic prevalence and health outcomes
- Healthcare access barriers
- Local reality of disability

TOOLS:

1.1 Stakeholder mapping tool

1.2 1-page crib sheet on terminology for disability inclusion

MISSING BILLION

Conducting the SLA

Once all the political and financial support has been mobilized, the task team can then focus on conducting the assessment

Suggested activities for conducting the SLA 1/2

PLAN A WORKSHOP

It is suggested to **organize a one-day workshop of the task team** to develop the following:

- **Workplan with timelines** assigning roles and responsibilities
- **Initial mapping of data sources** for each of the indicators

If a workshop is not feasible due to resource or member availability constraints, then these activities could be completed over a series of several meetings.

MISSING BILLION

Suggested activities for conducting the SLA 2/2

COLLECTING AND ANALYSING DATA

The **task team will need to** do the following to ensure the data is collected in a timely manner:

- **Identify person(s) or institutions that are responsible for collecting the data**. It might be an expert consultant, consultant team or research institution that is responsible.
  OR
- **Assign different members of the task team to collect different aspects of the data** for the team.

Periodic meetings to review progress can help to keep the data collection on track and troubleshoot any problems that arise.

TOOLS:

1.3 Matrix to enter the source, findings and notes for each indicator

MISSING BILLION

Sharing and Strategic Planning

After the data collection is completed, the task team should come together again to put together and/or review the report and plan for dissemination and strategic planning.

Suggested activities for sharing and strategic planning 1/2

ASSEMBLING & REVIEWING THE REPORT

The task team members assigned or contracted consultants or institutions should **produce a draft report of the findings**. Once the report is developed, **bring the task team together for a one-day workshop to review and discuss the report**.

DISSEMINATION EVENT

If feasible with the funding available, **hold a dissemination meeting with a broad set of stakeholders**. The meeting would include the following:

- Presentation of the findings
- Opportunities to provide feedback and comments on the findings
- Discussions to elicit initial thoughts about follow-on plans

The participants would be like the sensitization/ inception meetings and could either be a brief event to mainly share findings or slightly longer to include some interactivity.

During the dissemination meeting, distribute a short, anonymous survey to explore ways to improve the toolkit and overall assessment process

MISSING BILLION

STRATEGIC PLANNING

A meeting should be organized with key senior leaders in the Ministry of Health to translate the findings to strategic plans and actions. During the meeting, the task team should be present as well as any other government, **multilateral or non-governmental partners who will be essential to move from assessment to action.** In the meeting:

- **Prioritize three to four essential actions** across different elements rather than producing an elaborate, comprehensive plan. If the country is just embarking on disability inclusion, these might focus on foundational policy and systems needs
- **Determine a plan for costing the activities,** who is responsible for implementing them, and how they will be monitored
- **Identify sources of funding** for the costed activities, either through government resources or donors
- The country **might consider making the task team a permanent committee or creating a committee for oversight**. The plan can then be reviewed each year and new actions added as the previous ones are achieved, enabling an evolution of progress.

TOOLS:

1.4 Prioritization approach for strategic planning

MISSING BILLION

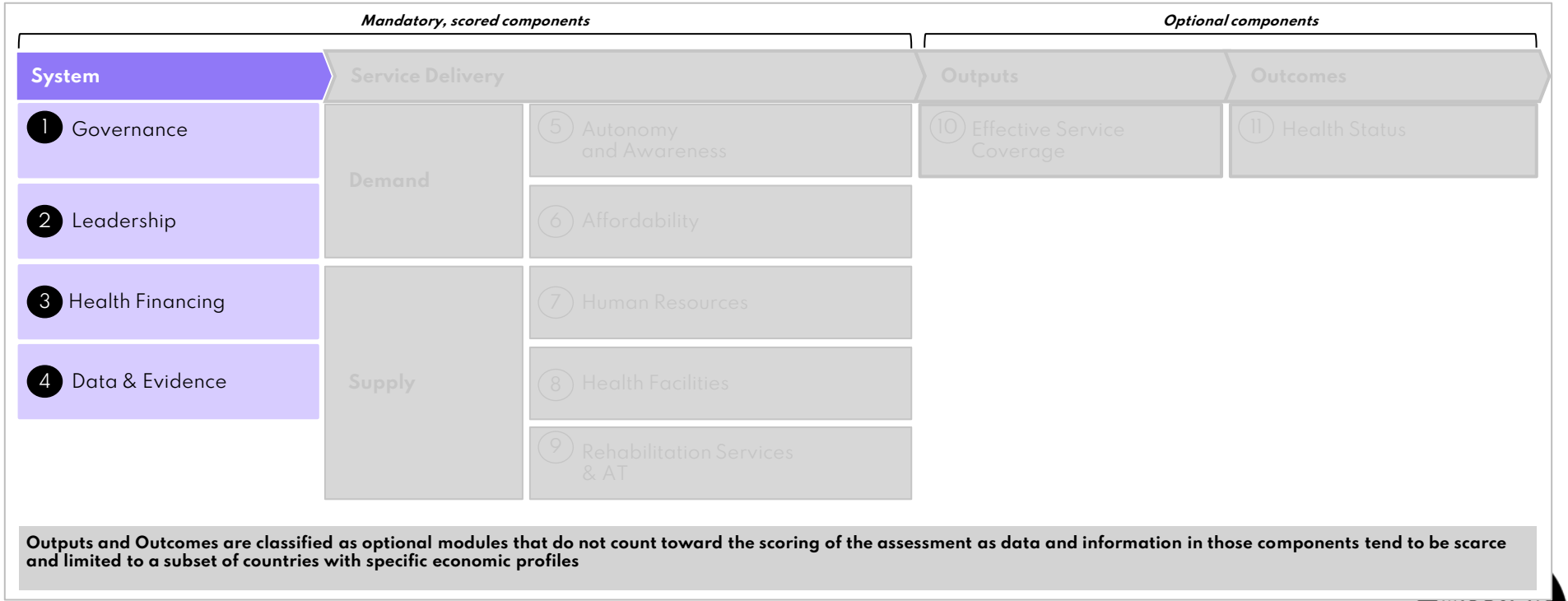
The indicators

The indicators are arranged according to the framework which includes three main domains:

- Systems
- Service Delivery
- Outputs & Outcomes (optional)

System components and indicators

Missing Billion Inclusive Health Systems Framework



1 Governance

Indicator	Definition	Information required	Scoring methodology
1.1 UNCRPD	Ratification and adoption of UN Convention on the Rights of Persons with Disabilities (CRPD)	Yes / No Evidence of it being actioned, e.g., dedicated budget, action plans and initiatives	Ratified and evidence of action e.g., dedicated budget (1) Ratified with no evidence of action (0.5) No (0)
1.2 National law	Existence of a national law protecting the right to health for persons with disabilities	Yes/No National law includes: 1) Law prohibits discrimination in healthcare 2) Law requires reasonable accommodation for people with disabilities	National law exists without meeting any of the 2 requirements (0.33) With each requirement 0.33 is added to the score
1.3 National health policy	Existence of a national policy or decree on health for persons with disabilities	Yes/No Policy ensures 1) General healthcare services for persons with disabilities 2) Access to Rehabilitation, other specialists and assistive technology services 3) Policy includes measures to implement these services	National policy exists without meeting any of the 3 requirements (0.25) With each requirement met 0.25 is added to the score
1.4 National Health Sector Plan(s)	Inclusion of people with disabilities in National Health Sector Plan(s) led the national health regulator	Yes/No Plan includes: 1) Actions and targets for general health care for persons with disabilities (not only prevention of disability) 2) Actions and targets for specialist health services for persons with disabilities 3) Basic statistics about persons with disabilities and health 4) Monitoring and evaluation indicators on disability as part of overall framework for the health sector	People with disabilities are included in National Health Sector Plan(s) without meeting any of the 4 requirements (0.2) With each requirement met 0.2 is added to the score
1.5 National disease plan	Inclusion of people with disabilities in National disease plan (e.g., HIV, rare diseases, hepatitis)	Yes/No Plan ensures: 1) Inclusion of people with disabilities in testing, treatment, information programs	Yes (1) No (0)
1.6 Cross ministry governance	Cross-ministry taskforce or structure to coordinate work on disability inclusion	Yes/No and which ministry is driving it Cross ministry governance includes: 1) Department of Health	A national taskforce exists (0.5), Ministry of Health included in the task force (1)

System Category

MISSING BILLION

2 Leadership

Indicator	Definition	Information required	Scoring methodology
2.1 MoH leadership	Existence of a focal point/team in MoH that's responsible for ensuring health access for people with disabilities	Yes/No with description of responsibility for disability inclusion, and title of role/team	There is a role/team responsibility for disability inclusion (1) No (0)
2.2 National health sector coordination (e.g., Global Fund CCM)	National health sector with formal representation of persons with disabilities (individual or OPDs) in highest-level health sector coordination structure	Yes/No, and title of structure/group	Yes (1) No (0)
2.3 Pandemic preparedness structures	Formal representation of people with disabilities (individuals or OPD) in national taskforce, e.g., COVID	Yes/No	Yes (1) No (0)

System Category

MISSING BILLION

3 Health financing

Indicator	Definition	Information required	Scoring methodology
3.1 Disability inclusion budget	Budget (MoH or devolved levels) for role/department in MoH working on disability inclusion	Yes/No, description includes if the budget is at the federal/decentralised	Yes, at the federal or decentralized level (1) No (0)
3.2 Reimbursement adjustments	Reimbursement adjustment available for services provided to patients with disabilities	Yes/no For example, there is a national health insurance reimbursement or there is adjusted capitation rates for people with disabilities	Yes, there is a national health insurance and reimbursement for some people with disabilities (1) No adjustments (with any financing mechanisms) (0)
3.3 AT/rehabilitation budget	Funding for AT/rehabilitation in MoH (or devolved levels) budget	Yes/No % of annual MoH budget	Yes (1) No (0)

System Category

MISSING BILLION

4 Data & Evidence

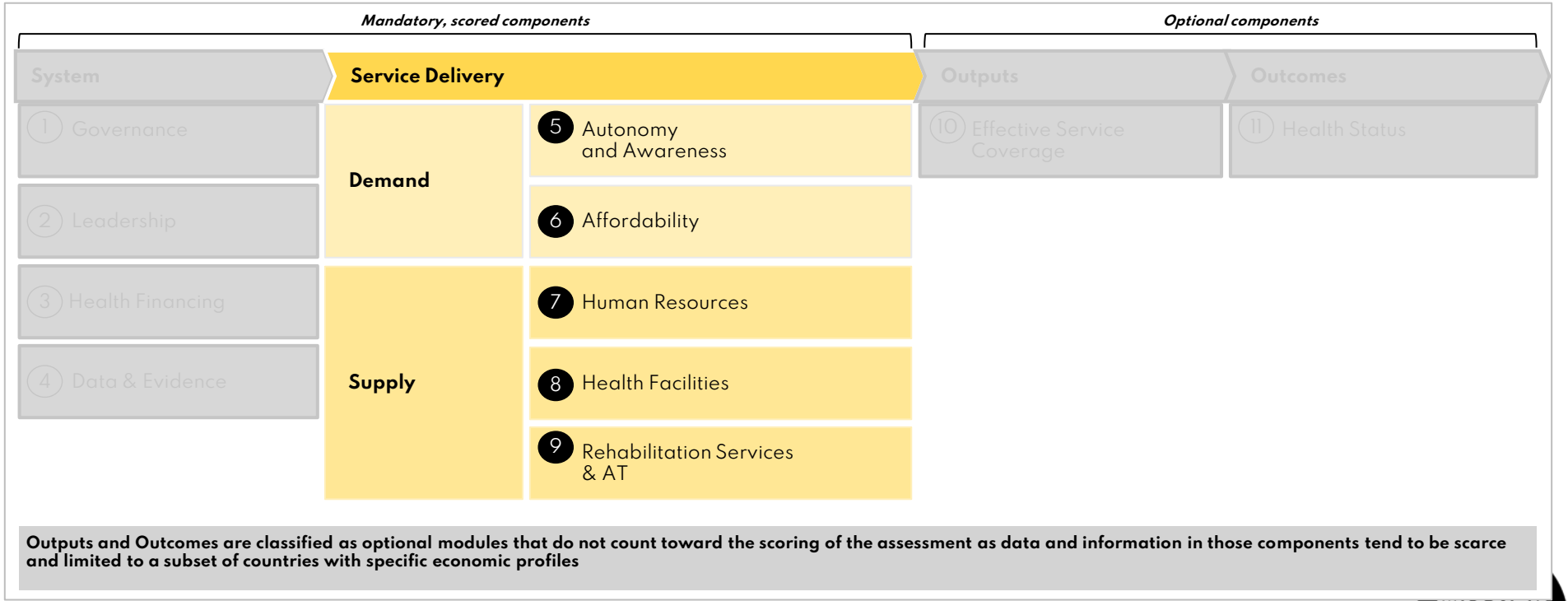
Indicator	Definition	Information required	Scoring methodology
4.1 Maturity of disability and health data collection	Maturity of disability and health data collection method	How was is disability and health data gathered? • National census/survey • Healthcare register of people with disabilities • Health information records tag people with disabilities (electronic integrated system)	Data is collected through health information records tagging people with disabilities (1) There is a national register for people with disabilities connected to health data (0.67) National survey/census asks disability questions (0.33) Disability and health data is not collected (0)
4.2 Quality of disability and health data collection method	Quality of disability and health data collection method	Plan includes: 1) Data collection method is valid 2) Data collection is recent - in the last 10 years 3) Data is nationally representative 4) 5+ impairment types are covered	Each criteria scores 0.25 points
4.3 Maturity of disability and health data usage	Maturity of how disability and health data is used	1) Disability health data that is collected is analysed and published 2) Findings from the data are used to inform program and policy change	1 - Data is analysed and reported and used to direct policy and program change 0.5 - Data is analaysed and published 0 - Data is not analysed and reported
4.4 Quality of disability and health data usage method	Quality of disability and health data usage method	If the quality criteria for data usage is met: 1) Data analysis method is transparent and valid 2) Data is analyzed and published within three years of collection 3) Analysis is nationally representative 4) Publications and raw data are easily accessible	Each criteria scores 0.25 points

System Category

MISSING BILLION

Service delivery components and indicators

Missing Billion Inclusive Health Systems Framework



Outputs and Outcomes are classified as optional modules that do not count toward the scoring of the assessment as data and information in those components tend to be scarce and limited to a subset of countries with specific economic profiles

5 Autonomy and awareness

Indicator	Definition	Information required	Scoring methodology
5.1 Organization for Persons with Disability (OPD) advocacy	OPDs advocate on the right to health for persons with disabilities with government and NGO delivery partners	OPDs have been engaged as advisory roles / partnerships with the Ministry of Health	Yes (1) No (0)
5.2 Autonomy and awareness	People with disabilities report autonomy and awareness about health access	If the following exist: 1) In a quantitative survey (in <10 years) persons with disabilities were asked about autonomy and awareness about health (in comparison to people without disabilities) OR 2) In a qualitative data published (in <10 years) in a peer-reviewed journal on reported autonomy and awareness about health	Yes (1) No (0)
5.3 Accessibility of health information	Health information is available in accessible formats	The number of accessibility formats available for the main national health information website e.g., easy read text, web page read out, sign interpretation of video/tv messages, braille, information for care givers	Yes: 2 or more accessibility formats (1) No: less than 2 accessibility formats (0)

Service delivery

MISSING BILLION

6 Affordability

Indicator	Definition	Information required	Scoring methodology
6.1 Health coverage	People with disabilities are fully covered for free healthcare through social health insurance, tax-based system, provision as part of disability allowance or any other stipulations	All healthcare is covered / Healthcare is partially covered / No	Yes (1) Partial coverage (0.5) No (0)
6.2 Transport subsidy available for disabled people	Transport subsidy is available and public transport can help travel to medical care	Yes/No Hospital/health center dedicated public transport services	Yes - there is subsidized transport and facility dedicated services (1) Yes - there is subsidized transport but not facility dedicated services (0.5) No (0)
6.3 Disability allowance	There is a disability allowance that is available to cover healthcare fees not covered by existing insurance or tax-based systems, e.g., assistive technologies	Yes/No Groups and/or regions that have the allowance available	Yes - There is disability allowance that is available to people with moderate to severe disabilities (1) Yes - There is a disability allowance available for some people living in the country (0.5) No (0)
6.4 Co-pays	Any co-pays for services in either health insurance or taxation-based systems not covered by disability allowances are waved for persons with disabilities	Yes/No	Yes (1) No (0)

Service delivery

MISSING BILLION

7 Human Resources

Indicator	Definition	Information required	Scoring methodology
7.1 Training of medical doctors	Information about disability delivered as part of the national curricula for medical schools/colleges	Yes/No Requirements: 1) Training content covers medical and non-medical modules 2) The training is part of the core curriculum (not voluntary)	Yes without meeting any of the requirements (0.33) With each requirement met 0.33 is added to the score
7.2 Training of nurses	Information about disability delivered as part of the national curricula for nurses/nursing colleges	Yes/No Requirements: 1) Training content covers medical and non-medical modules 2) The training is part of the core curriculum (not voluntary)	Yes without meeting any of the requirements (0.33) With each requirement met 0.33 is added to the score
7.3 Training of community based actors (e.g., CHW)	Information about disability delivered as part of the national CHW training curricula	Yes/No Requirements: 1) Training content covers medical and non-medical modules 2) The training is part of the core curriculum (not voluntary)	Yes without meeting any of the requirements (0.33) With each requirement met 0.33 is added to the score
7.4 Representation in health workforce	People with disabilities are represented in the health workforce	% of medical doctors that have disability	Yes - representation is in line with or greater than disability prevalence of the working age population - (if not known for the country assume 2% for LMIC, 4% HIC) (1) No (0)
7.5 Satisfaction	People with disabilities report that they feel well treated by health workers	If the following exist 1) In a quantitative survey from within the last 10 years persons with disabilities were asked about satisfaction with health worker services (in comparison to people witouth disabilities) OR 2) A qualitative data published in the last 10 years in a peer-reviewed journal on reported satisfaction	Yes - in a quantitative survey from within the last 10 years persons with disabilities were asked about satisfaction with health worker services (in comparison to people without disabilities) (1) OR Yes - qualitative data published in the last 10 years in a peer-reviewed journal on reported satisfaction (1) Both (1) No (0)

Service delivery

8 Health facilities

Indicator	Definition	Information required	Scoring methodology
8.1 National accessibility standards	Existence of national accessiblity standards for healthcare facilities	Yes/No	Yes (1) No (0)
8.2 Accessibillity of facilities	Accessibility audit of health facilities has been undertaken in the last 10 years with requirements: 1) Results are published 2) It is mandatory for all facilities to meet the accessibility standards, consequences when it is not reached	Yes/No Results of audit report in published government report/documents or peer-reviewed journal Mandatory/non-mandatory for facilities to meet accessibility standards	Accessibility audit takes place (0.33) Additional 0.33 when requirements are met

Service delivery

MISSING BILLION

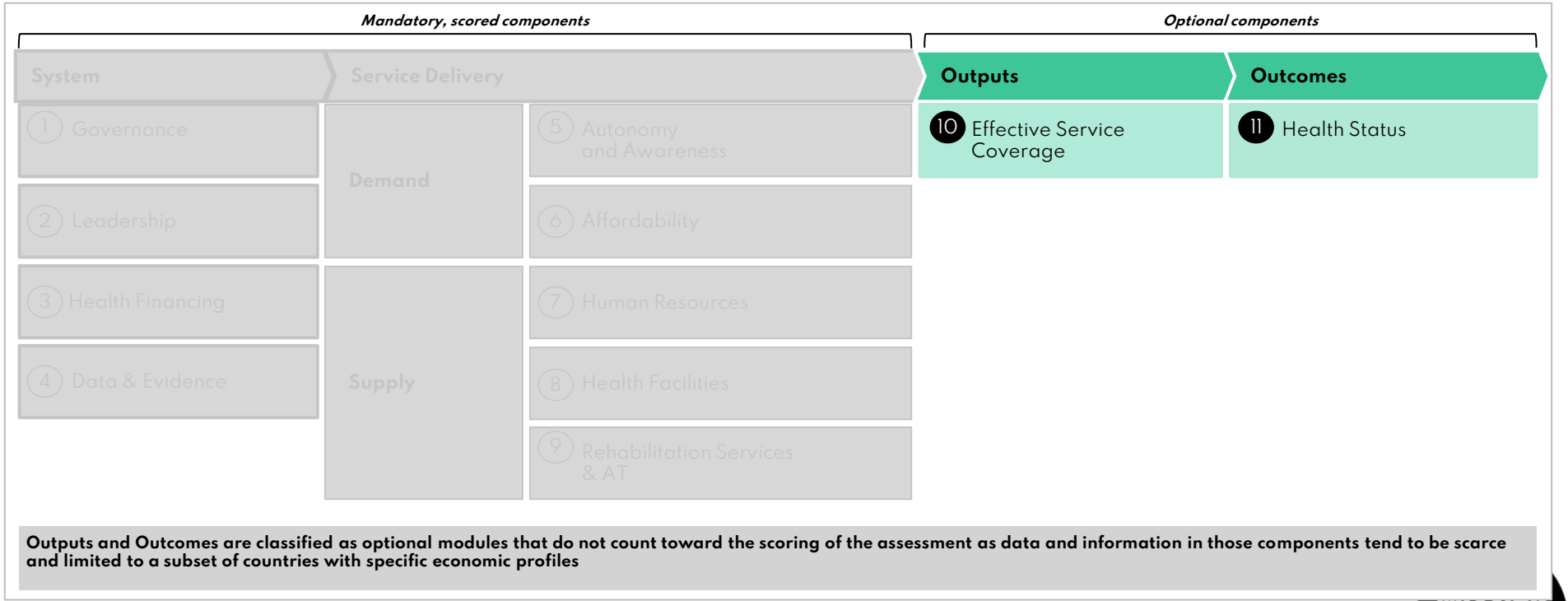
9 Assistive technology and Rehabilitation

Indicator	Definition	Information required	Scoring methodology
9.1 National assessments	National Assessment of Assistive Technology or rehabiliation (e.g., STAR or RATA) done in the last 10 years	Yes/No If yes, provide: 1) description of National Assessment of Assistive technology 2) National representativeness of assessment 3) Date of assessment 4) Key findings from the last assessment	Yes (1) No (0)
9.2 Cross-ministry AT coordination	Coordination mechanism cross-Ministry for rehabiliation services and AT where more than 1 ministries involved	Yes/ No N/A - only 1 ministry responsible for AT/rehabiliation	Yes (1) No (0) N/A - only 1 ministry responsible
9.3 Trained workforce available to provide rehabilitaiton services and AT	Physiotherapists available and trained to provide rehabilitation services and assistive technology	# of Physiotherapists/1,000,000 population Includes occupational therapist, audiologist, speech and language, optometrist, Rehabilitation physician, clinical psychologist	1 - LMIC: Above 30/1,000,000 population HIC: Above 300/1,000,000 0 - Below the threshold for population

Service delivery

Outputs and outcomes (optional)

Missing Billion Inclusive Health Systems Framework



10 Effective Service Coverage (optional)

Indicator	Metric
• Modern contraception coverage – Women whose demand is satisfied with a modern method of contraception, disaggregated by disability	• % of women with disabilities, compared to % of overall women
• ARTs coverage – People with HIV receiving ART, disaggregated by disability	• % of people with disabilities that have coverage, compared to coverage of people without disabilities
• DTP 3 coverage – Children aged 12-23 months who have received diphtheria-tetanus-pertussis vaccine (DTP3), disaggregated by disability	• % of children with disabilities, compared to % of overall children
• Refractive error coverage – People with refractive error have coverage of glasses	• % of those with need who have glasses (e.g. from RAAB survey)
• NCD coverage – People with diabetes on treatment OR people with hypertension on treatment, disaggregated by disability	• % of people with disabilities, compared to people without disabilities

Outputs

MISSING BILLION

11 Health Status (optional)

Indicator	Metric
• Mortality – Overall mortality rate, disaggregated by disability	• Deaths per 100 000 population; people with disabilities compared to people without disabilities
• Diabetes – Prevalence of diabetes OR hypertension among persons aged 18+ years, disaggregated by disability (Global Monitoring Framework NCDs; indicator #12, indicator #11, WHO)	• People with disabilities, compared to people without disabilities
• HIV – Prevalence of HIV, disaggregated by disability	• % of people living with HIV among adults aged 15–49; people with disabilities compared to people without disabilities
• Overweight and obesity – Prevalence of overweight and obesity among persons aged 18+ years, disaggregated by disability (Global Monitoring Framework NCDs; indicator #13, WHO)	• % of all population with disabilities, compared to population without
• Wasting – Prevalence of children wasted (moderate and severe), 0-59 months of age, disaggregated by disability; WHO Child Growth Standards median	• % of children with disabilities, compared to % of overall children

Outcomes

Sample SLA output

We piloted a contextually-adjusted version of the SLA in a Middle Eastern country.

The following section is a portion of the sanitized output of that assessment, which can be reproduced for any other healthcare systems globally

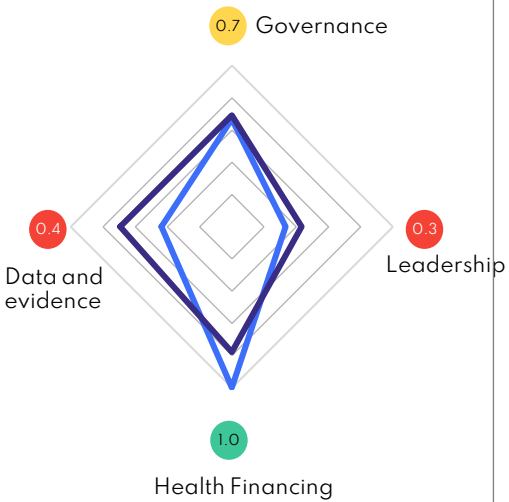
Sample output: The SLA can provide a high-level overview of the system

Low (<0.5) Intermediate (0.5-0.74) Advanced (0.75-1) Sample country Comparison countries[2]

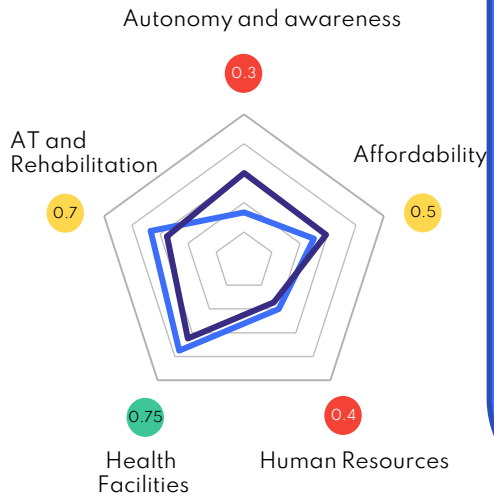
Overall score[1]

60 %

System delivery



Service delivery



Key takeaways

Opportunities for improvements in **leadersh and data & evidence** can be achieved by:

- **Increasing formal representation of people with disabilities/OPDs** in health sector teams
- **Analyzing and publishing datasets within 3 years of collection**, ensuring th data collection and analysis methods a transparent and the publication/raw d is easily accessible

Within service delivery, **autonomy and awareness** has the greatest room for improvement, which can be achieved by:

- **Improving accessibility of healthcare information** in multiple formats includin online resources and printed materials

1. Average of all components with equal weighting
2. Average from outside-in assessment of ~10 health systems

MISSING BILLION

Sample output: The SLA provides a breakdown by indicator

Low (<0.5) Intermediate (0.5-0.74) Advanced (0.75-1)

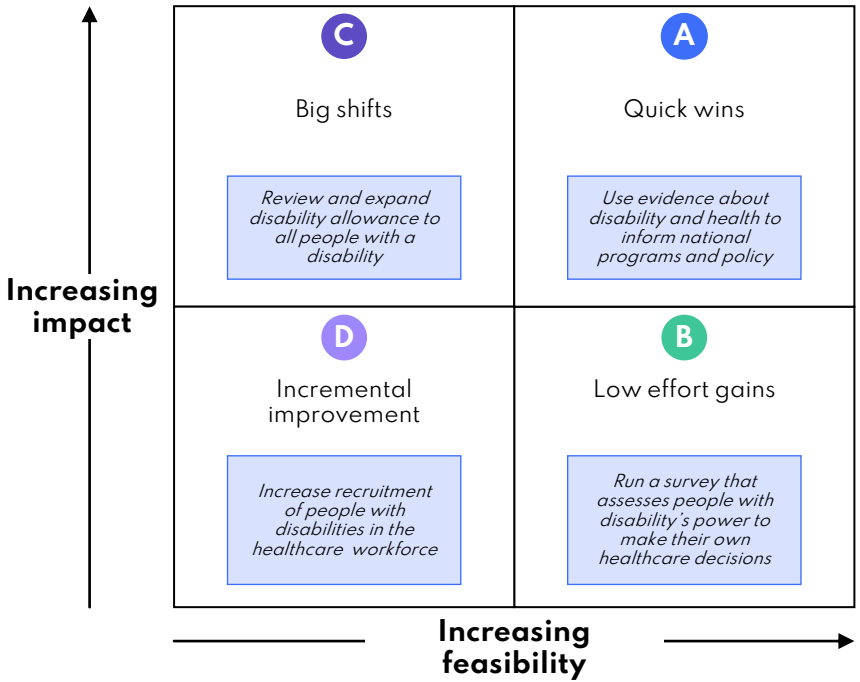
1 Governance 0.7	Score
1.1 Ratification of UN Committee on the Rights of Persons with Disabilities (CRPD) by country	
1.2 Existence of a national law protecting the right to health for persons with disabilities	
1.3 Existence of a national policy or decree on health for persons with diabilities	
1.4 Inclusion of people with disabilities in National/Local Health Sector Plan(s) led by main National or local health regulator	
1.5 Inclusion of people with disabilities in National HIV plan	
1.6 Cross-ministry taskforce or coordination structure to coordinate on all issues of disability	
2 Leadership 0.3	
2.1 Existence of a focal point/team/directorate in MoH that's responsible for ensuring health access for people with disabilities	
2.2 National health sector coordination/leadership with formal representation of persons with disabilities (individual, or OPDs) in highest-level	
2.3 Formal representation of people with disabilities (individuals are representing OPD) in national COVID-taskforce, people with disabilities are part of the taskforce	

3 Health financing 1.0	Score
3.1 Funding for AT/rehabilitation in MoH (or devolved levels) budget	
3.2 Budget (MoH or devolved levels) for role/department in MoH working on disability inclusion	
3.3 Reimbursement adjustment for services provided to patients with disabilities	
4 Data & evidence 0.4	
4.1 Maturity of disability and health data collection method	
4.2 Validity of disability and health data collection method	
4.3 Usage of disability and health data collected	
4.4 Validity of disability and health data usage method	

MISSING BILLION

Interventions to address gaps identified are prioritized based on feasibility and impact

Prioritization matrix, *examples of interventions*



Impact

- **Foundationally important** – necessary to create an environment where disability inclusion is on the agenda
- **Change opportunity** – there is a large opportunity for improvement
- **Number of people with disability affected** – many people will feel the benefits of the intervention
- **Time to impact** – first impact to people with disability is felt within near future of implementation (e.g., <1 year)
- **Strength of evidence of impact** *Not included in current version due to lack of evidence for all interventions*

Feasibility

- **Timeframe –** implementation can take place and be completed with in near future (e.g., <1 year)
- **Cost** – budget and resource requirements are not prohibitive for the country
- **Stakeholder complexity** – Easy to gain necessary buy in from stakeholders
- **Technical complexity** – Easy to implement with existing foundations and expertise

MISSING BILLION

Sample output: Initiatives to further improve pilot country healthcare system inclusivity

Phase	Category	Intervention	Next steps
A Quick wins	**Leadership**	**Ensure formal representation of people with disabilities in health sector coordination and national emergency taskforces** (e.g., COVID)	**Reinforce relationship with OPDs** to act as close advisory partners in developing national health policy and cross-sector committees / entities, especially the work with National Emergency Crisis and Disaster Management
	Data and evidence	**Analyze and publish datasets** within 3 years of collection, ensuring the data collection and analysis methods is transparent and the publication/raw data is easily accessible	**Leverage existing health information systems** to analyze and publish health data disaggregated by disabilities
		Use evidence about disability and health to inform national programs and policy	**Develop an inclusive health strategy** that is integrated and mainstreamed into the overall health strategy, across disease plans and areas of focus, and leverages data and evidence Ensure alignment with current PWD strategy
	Governance	**Develop national health sector plans and national disease plans** which include people with disabilities. National disease plans should include people with disabilities in testing, treatment and information programs	
	Affordability	**Review public transport links for health facilities,** e.g., ensure there are dedicated bus services	**Work with transport authorities** to optimize the transport network for connectivity to health centers Explore social transportation assistance for PWDs alongside relevant ministries

MISSING BILLION

Sample output: SLA produces detailed assessment and scoring by indicator (1/2)

Category	Component	Indicator	Definition	Information required	Pilot country system level assessment	Score /1	Score for component / 1
System	Governance (1/2)	1.1 UNCRPD	Ratification of UN Convention on the Rights of Persons with Disabilities (CRPD)	Yes / No Evidence of it being actioned, e.g., dedicated budget, action plans and initiatives	Yes (2008) Evidence of implementation: 2020 Department of Community Development in Pilot country launched the Strategy for people with disabilities 2020-2024 with initiatives including an Early Interventions Program and Assistive Technologies plan	1	0.7
		1.2 National law	Existence of a national law protecting the right to health for persons with disabilities	Yes/No National law includes: 1) Law prohibits discrimination in healthcare 2) Law requires reasonable accommodation for people with disabilities	Yes 1- Yes (Federal Law No 29 of 2006) A person's special needs shall not be a reason to deprive him/her of their rights and services especially in welfare as well as social, economic, health, educational, professional, cultural and leisure services. The Pilot country's people with disabilities Protection from Abuse Policy condemns all forms of abuse and neglect of people with disabilities 2- Yes (Federal law no 13 for 2020) states that the Ministry of Health and Prevention and local health bodies have an obligation to enhance and protect the health of people with disabilities and provide the appropriate environment for them	1	
		1.3 National health policy	Existence of a national policy or decree on health for persons with disabilities	Yes/No Policy ensures: 1) General healthcare services for persons with disabilities 2) Access to Rehabilitation, other specialists and assistive technology services 3) Policy includes measures to implement these services	Yes - The National Policy for Empowering people with disabilities 1- Yes. There is a set of initiatives across 4 main goals: - Guaranteeing a comprehensive and high-quality care - Accurate and high-quality diagnosis of disabilities - Providing information of all people with disabilities in the Pilot country - Providing specialized medical staff and health specialists in disabilities 2- Health and rehabilitation pillar in the national policy: The government will provide a comprehensive high-quality health care, as well as post-accident rehabilitation programmes and health programmes for this segment. A national program would be launched for early detection and diagnosis of impairments 3 - Initiatives are in place	1	
		1.4 National Health Sector Plan(s)	Inclusion of people with disabilities in National Health Sector Plan(s) led the national health regulator	Yes/No Plan includes: 1) Actions and targets for general health care for persons with disabilities (not only prevention of disability) 2) Actions and targets for specialist health services for persons with disabilities 3) Basic statistics about persons with disabilities and health 4) Monitoring and evaluation indicators on disability as part of overall framework for the health sector	No - at the Pilot country level, there is no inclusion of disability-specific elements of the healthcare sector strategy led by Department of Health. Department of Community developed has developed the Pilot country Strategy for people with disabilities 2020-2024 1- No 2- No 3- No 4- No	0	

MISSING BILLION

Sample output: SLA produces detailed assessment and scoring by indicator (2/2)

Category	Component	Indicator	Definition	Information required	Pilot country system level assessment	Score /1	Score for component /1
System	Governance (2/2)	1.5 National disease plan	Inclusion of people with disabilities in National disease plan (e.g., HIV, rare diseases, hepatitis)	Yes/No Plan ensures: 1) Inclusion of people with disabilities in testing, treatment, information programs	National disease plans (e.g., AMR, zoonotic diseases) have no or very limited mention of people with disabilities, and do not have explicit actions of their inclusion for testing, treatment, information	0	0.7
		1.6 Cross ministry governance	Cross-ministry taskforce or structure to coordinate work on disability inclusion	Yes/No and which ministry is driving it Cross ministry governance includes: 1) Department of Health	Yes Pilot country Strategy for people with disabilities is a cross-ministerial strategy with six taskforces assigned to six strategic pillars; i) health and rehabilitation, ii) education, iii) employment, iv) social care, v) universal access, vi) enablers Each taskforce has a lead entity and representation from other relevant entities from the local/federal govt., private sector and other third-party organizations. The taskforce on health and rehabilitation is lead by the Department of Health, with other stakeholders including Department of Community Development, Department of Education and Knowledge, etc.	1	
	Leadership	2.1 MoH leadership	Existence of a focal point/team in MoH that's responsible for ensuring health access for people with disabilities	Yes/No with description of responsibility for disability inclusion, and title of role/team	Yes There are two teams within Department of Health: Healthcare Facilities and Services Department team (responsibility for disability inclusion and rehabilitation access to Facilities and Services) and Healthcare Payers Sector team (Insurance)	1	0.3
		2.2 National health sector coordination (e.g., Global Fund CCM)	National health sector with formal representation of persons with disabilities (individual or OPDs) in highest-level health sector coordination structure	Yes/No, and title of structure/group	No people with disabilities within DoH taskforces, there will be a representation of people with disabilities within the health and rehabilitation pillar of the DCD strategy taskforce of DoH (Not yet implemented) No, even for representation of people with disabilities through public health organization worldwide in Rehabilitation International (RI), World Federation of the Deaf (WFD), European Handcycling Federation (EHF), Paralympic, Special Olympics & Arab Federation for Sports with Disabilities	0	0.3
		2.3 Pandemic preparedness structures	Formal representation of people with disabilities (individuals are representing OPD) in national COVID-taskforce, people with disabilities are part of the taskforce	Yes/No	No formal representation of people with disabilities in national COVID taskforce	0	

MISSING BILLION

Potential sources of data

- Government policy documents and reports
- Scientific publications
- Other “grey” literature (e.g., NGO reports)
- Interviews with key informants (e.g., Government, OPDs, health sector)
- Publicly available data

MISSING BILLION

Missing Billion Initiative Resources

Compendium of Good Practices

2022 evidence report: Reimaging health systems that expect, accept and connect 1 billion people with disabilities

2019 evidence report: Access to health services for 1 billion people with disabilities

McKinsey Health Institute x Missing Billion report: The Missing Billion: Lack of disability data impedes healthcare equity

MISSING BILLION

How to work with us

If you are interested in applying The Missing Billion System Level Assessment, please reach out to us. **We will provide you with the requisite tools and support**, including:

- **A Microsoft Excel tool** that contains the detailed SLA framework and scoring sheet
- **Support on applying the SLA**, best practices in the SLA process, **and support in planning the implementation** of interventions
- **Guidance and support on compiling results and communicating them** effectively to assessment lead

Throughout the SLA, **we ask that you support** the The Missing Billion Initiative **by providing**:

- **A focal point in your SLA task team** to coordinate with The Missing Billion Initiative
- **Results of the SLA** so that we may compile and draw learning from assessments of healthcare systems globally

Appendix

MISSING BILLION

Tools

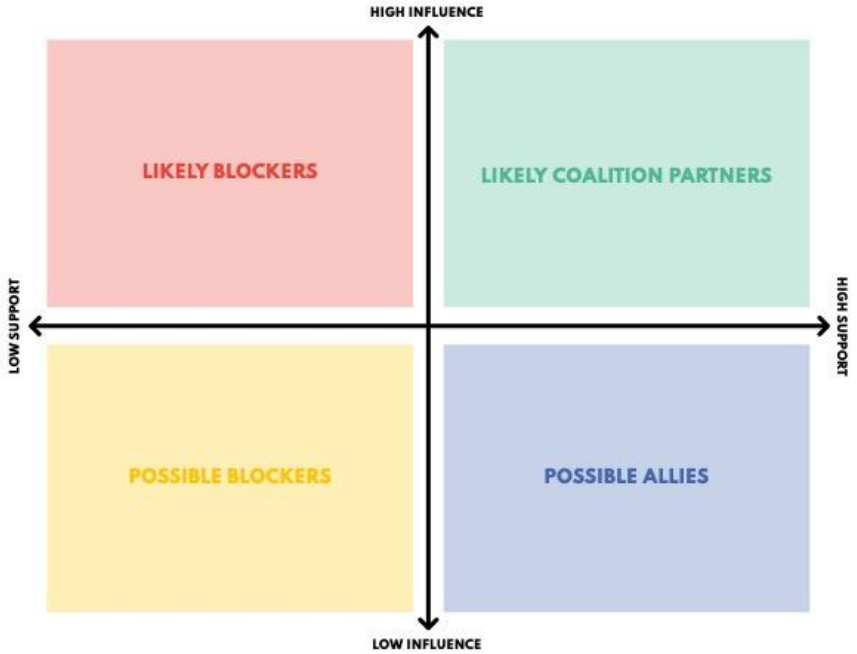
1.1 Stakeholder mapping tool

Likely partners

List the key stakeholders to consider on the left. Draw a circle and write the name inside for each, placing them on the map in the location that represents their likely support and role in disability inclusion. Change the size of the circles, with larger circles representing more power or authority.

MISSING BILLION

LIST OF STAKEHOLDERS



Tools

1.2 1-page crib sheet on terminology for disability inclusion

Definitions (from World Report on Disability)

Accessibility: Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities.

Accessibility standards: A standard is a level of quality accepted as the norm. The principle of accessibility may be mandated in law or treaty, and then specified in detail according to international or national regulations, standards, or codes, which may be compulsory or voluntary.

Assistive devices; also assistive technology: Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability.

Disability: In the ICF, an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Disability discrimination: Any distinction, exclusion, or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise on an equal basis with others, of all human rights and fundamental freedoms: includes denial of reasonable accommodation.

Health: A state of well-being, achieved through the interaction of an individual's physical, mental, emotional, and social states.

Health system[1]: An organization of people, institutions and resources that delivers health care services to meet the health needs of target population.

Inclusive society: One that freely accommodates any person with a disability without restrictions or limitations.

Organization of Persons with Disabilities: Organizations or assemblies established to promote the human rights of disabled people, where most the members as well as the governing body are persons with disabilities.

Reasonable accommodation: Necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms.

Rehabilitation: A set of measures that assists individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environment.

Social protection: Programmes to reduce deprivation arising from conditions such as poverty, unemployment, old age, and disability.

Universal design: The design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

[1] Definition not from World Report on Disability

MISSING BILLION

Tools

1.3 Matrix to enter the source, findings and notes for each indicator

Indicator collection tool
Missing Billion country diagnostic toolkit 1.0
Date: October 2022

	Component		Indicator	INDICATOR 1.0 Definition	Metric	Potential data sources	Source	Numerator/denominator (if relevant)	Findings	Description
System	1 Governance	1	UNCRPD	Ratification of UNCRPD by country	Yes/No	UNCRPD database: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html				
		1	National law	Existence of a national law protecting the rights of persons with disabilities to health	Yes/No and description of whether law prohibits discrimination, whether the law requires reasonable accomodation and whether the law is diability-focused on	1. Review of current laws (e.g. internet search); 2. Interview with key informants				
		1	National health policy	Existence of a national policy or decree on health for persons with diabilities	Yes/No and description of how policy ensures access to specialist (rehabilitation services, AT) and general healthcare services for persons with disabilities, and whether the policy includes measures to	1. Review of current policies (e.g. online and from MoH); 2. Interview with key informants				
		1	National Health Sector Plan(s)	Inclusion of people with disabilities in National Health Sector Plan(s)	Yes/No and description Description to include: 1) Includes actions and targets for specialist health services for persons with disabilities 2) Includes actions and targets for general health care for persons with disabilities (not only prevention of disability) 3) Includes basic statistics about persons with disabilities and health 4) Includes monitoring and evaluation indicators on disability as part of overall framework for the health sector	1. Review of documents (online and from MoH); 2. Interview with key informants				
		2	National HIV plan	Inclusion of people with disabilities in Nati	Yes/No and description Description to include: 1) Includes actions and targets for specialist HIV health services for persons with disabilities 2) Includes actions and targets for general HIV health care for persons with disabilities (not only prevention of disability) 3) Includes basic statistics about persons with disabilities and HIV 4) Includes monitoring and evaluation indicators on HIV amongst persons with disabilities as part of overall framework for the health sector	1. Review of documents (online and from MoH); 2. Interview with key informants				

Tools

1.4 Prioritization approach for strategic planning

MISSING BILLION

Prioritizing activities

List the proposed activities on the left. Then agree where each should be placed on the two-by-two table. Draw a circle for each when you place it and change the size of the circles based on cost estimates, with larger circles representing higher cost.

LIST OF ACTIVITIES

IMPACT

Important, and may lead to incremental changes

Impactful and important to set foundations for future actions

Not impactful nor important

Less impactful but important for setting foundations for future actions

FOUNDATIONAL IMPORTANCE

MISSING BILLION

MISSING BILLION

Thank you!