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Missing Billion Toolkit – System Level Assessment - IDD Module

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Introduction

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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.
- **Health access barriers are often even more significant for people with intellectual and developmental disabilities (IDD).** Including inaccessible health information, poor skills of healthcare workers, and reliance on carers to seek care. Consequently, health outcomes may be particularly poor for people with IDD – for instance they had much higher mortality rates from COVID-19 than others in the population, or even other people with disabilities.

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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.

The Intellectual and Developmental Disabilities (IDD) Module

- The SLA-IDD Module[1] was developed jointly by MBI with the Special Olympics International Inclusive Health Team in 2023
- The Module is meant to be an add-one to the overall SLA, applied by Ministries of Health to further understand the inclusion of people with IDD and their caregivers within a health system
- The module can also be applied in itself, e.g. by advocacy groups that would like to highlight particular access issues for persons with IDD

1 IDD being defined in line with the ICD-11 revision Working Group on IDD
https://doi.org/10.1002/j.2051-5545.2011.tb00045.x

Objectives and "use cases" for the SLA-IDD Module

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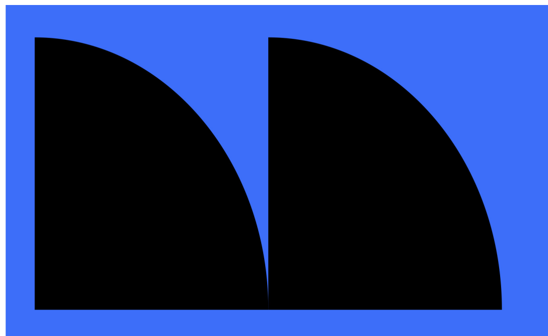

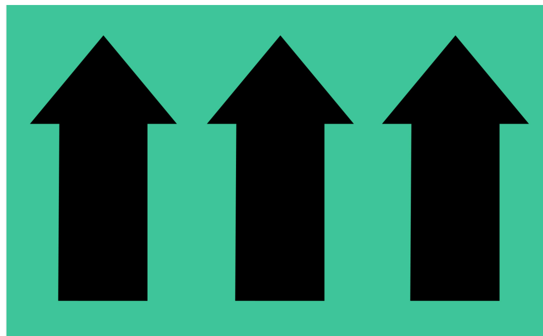

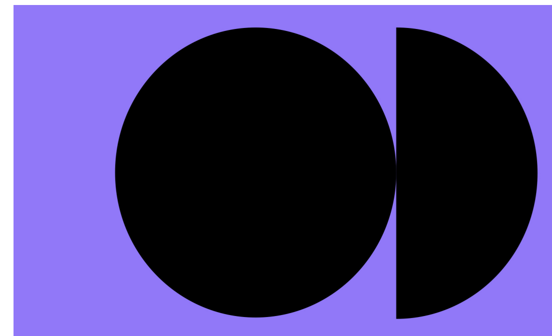

Lead	**Ministry of Health**	**OPD/NGO**	**Medical schools/medical providers**
Objective	• Collate "internal" and public data on the current performance of the health system for persons with IDD • Identify actions to take and use data as a baseline for tracking progress • This ideally follows the application of the overall assessment toolkit on disability inclusion (in a deep-dive approach)	• Collate public data on the current health system performance for persons with IDD • Use the findings to advocate with the Ministry of Health, or payors/providers, to take action and/or conduct official MoH-led assessment	• Collate public or provider-specific data on health system performance for persons with IDD • Use findings to improve service provision or teach needed improvements to future health system leaders/clinicians

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The IDD Module follows the same structure as the overall SLA

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Missing Billion Inclusive Health Systems Framework

Mandatory, scored components			*Optional components*	
System	**Service Delivery**		**Outputs**	**Outcomes**
1 Governance	Demand	5 Autonomy and Awareness	10 Effective Service Coverage	11 Health Status
2 Leadership	Demand	6 Affordability		
3 Health Financing	Supply	7 Human Resources		
4 Data & Evidence	Supply	8 Health Facilities		
	Supply	9 Rehabilitation Services & AT		

How the SLA-IDD module works

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The assessment has nine component parts, covering the system delivery and service delivery

Each component is measured by ~5 indicators that give a picture of its strength

Indicators are scored 1 if met, 0 if not. If there are multiple criteria of which only some are met, the score is between 0 and 1

Structure of the assessment

Components

1. Governance
2. Leadership
3. Health financing
4. Data and Evidence
5. Autonomy & awareness
6. Affordability
7. Human resources
8. Health facilities
9. Specialized services and AT

Governance indicators

1.1 Ratification of UN Convention on the Rights of Persons with Disabilities (CRPD) and evidence of action

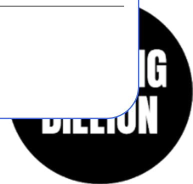
1.2 Existence of a national law protecting the right to health for persons with disabilities, with specific reference for people with IDD OR an independent national law protecting the right to health for people with IDD

1.3 Existence of a national policy or decree on health for persons with disabilities, with specific reference for people with IDD OR an independent national policy or decree on health for people with IDD

1.4 Inclusion of people with disabilities in National Health Sector Plan(s) led by the national health regulator, with specific reference for people with IDD OR there is an independent National Health Sector Plan for people with IDD led by the national health regulator

1.5 Inclusion of people with disabilities in National disease plan (e.g., HIV, rare diseases, hepititus), with specific reference to the needs of people with IDD

1.6 Cross-ministry taskforce or structure to coordinate work on disability inclusion, including specific responsibility for people with IDD



1. If there is more than one sub-criteria for the indicator, the score is given between 0 and 1, e.g., if there are 4 criteria the score is in intervals of 0.25

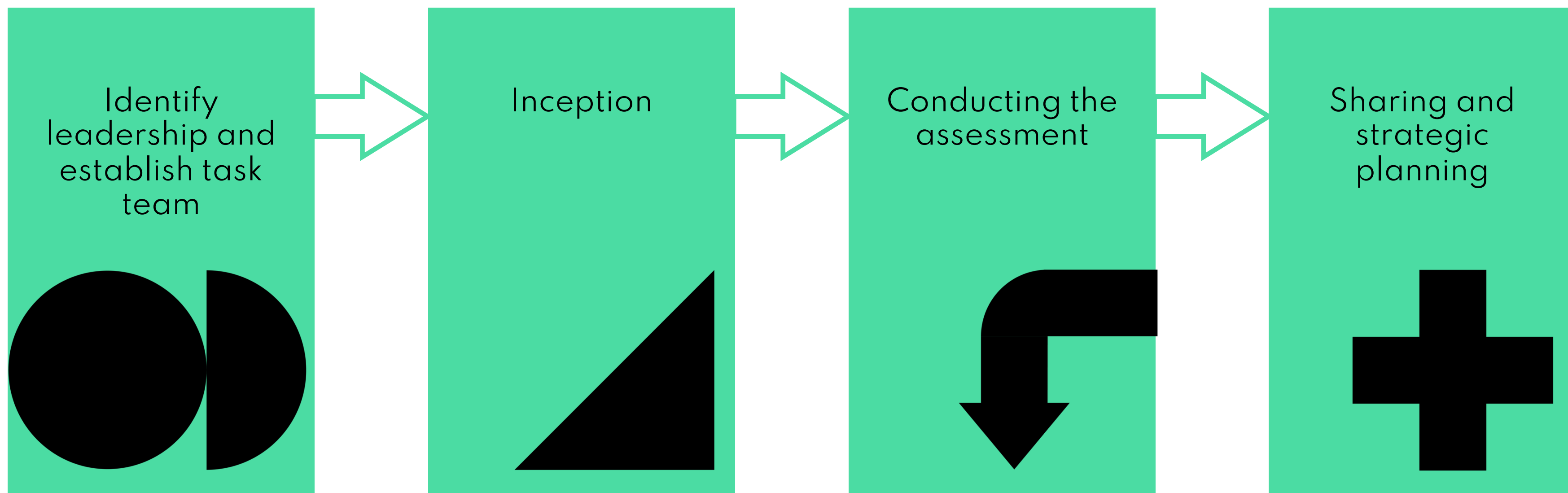
SLA-IDD timelines

The **overall process** of conducting the SLA-IDD Module **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

SLA-IDD Module Process



Task team composition in the use case with MoH leadership

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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 an NGO or an OPD in coordination with the MOH

MEANINGFUL PARTICIPATION OF PERSONS WITH IDD

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

As people with IDD are actively involved, **ensure that all processes/activities are inclusive and accessible** (e.g. meeting agendas, presentations and other information in simple and/or easy to read language, guidance to all members on communication with colleagues with IDD, valuing and accommodating individual preferences)

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 IDD and organizations of persons with disabilities, caregivers of people with IDD, technical and NGO partners and donor representatives.**

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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

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Missing Billion Inclusive Health Systems Framework

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System	**Service Delivery**		**Outputs**	**Outcomes**
1 Governance	**Demand**	5 Autonomy and Awareness	10 Effective Service Coverage	11 Health Status
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3 Health Financing	**Supply**	7 Human Resources		
4 Data & Evidence		8 Health Facilities		
		9 Rehabilitation Services & AT		

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

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1 Governance

Indicator		Definition	Information required	Scoring methodology
1.1	UNCRPD	Ratification and adoptions 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, with specific reference for people with IDD OR an independent national law protecting the right to health for people with IDD	Yes/No	People with IDD referenced in national law protecting the right to health for people with disabilities in general AND/OR there is an independent law for people with IDD (1) National law protecting the right to health exists for people with disabilities in general without any reference to people with IDD AND there is no independent law for people with IDD (0.5) No national law protecting the right to health for persons with disabilities or IDD exists (0)
1.3	National health policy	Existence of a national policy or decree on health for persons with disabilities, with specific reference for people with IDD OR an independent national policy or decree on health for people with IDD	Yes/No Policy includes: 1) Reference to the needs of people with IDD in healthcare, including reasonable accommodation, communication, or decision-making 2) Reference to caregivers of persons with IDD and their role in health management, including support they need	People with IDD referenced in national policy for people with disabilities in general AND/OR there is an independent policy for people with IDD (0.5) National policy exists for people with disabilities in general without any reference to people with IDD AND there is no independent policy for people with IDD (0.25) With each requirement met 0.25 is added to the score No national policy on the health of persons with disabilities AND/OR IDD exists (0)

System Category

1 Governance

Indicator		Definition	Information required	Scoring methodology
1.4	National Health Sector Plan(s)	Inclusion of people with disabilities in National Health Sector Plan(s) led by the national health regulator, with specific reference for people with IDD OR there is an independent National Health Sector Plan for people with IDD led by the national health regulator	Yes/No Plan includes: 1) Actions and targets for general health care for people with IDD 2)Actions and targets for specialist health services for people with IDD 3) Basic statistics about persons with IDD and health (e.g. mortality, prevalence of health conditions, health service utilisation) 4) Monitoring and evaluation indicators on disability and IDD as part of overall framework for the health sector	People with IDD referenced in National Health Sector Plan AND/OR there is an independent National Health Sector Plan for people with IDD (0.5) People with disabilities included in National Health Sector Plan without any reference to people with IDD AND there is no independent National Health Sector Plan for people with IDD (0.25) Meeting at least two requirements adds 0.25 to the score Meeting all four requirements adds 0.5 to the score Persons with disabilities AND/OR people with IDD are not included in the National Health Sector Plan (0)
1.5	National disease plan	Inclusion of people with disabilities in National disease plan (e.g., HIV, rare diseases, hepititus), with specific reference to the needs of people with IDD	Yes/No Plan ensures: 1) Specific measure of people with IDD in programme delivery plans	Yes (1) No (0)
1.6	Cross ministry governance	Cross-ministry taskforce or structure to coordinate work on disability inclusion, including specific responsibility for people with IDD	Yes/No, taskforce exists and functions (i.e. has met in the past year), and which ministry is driving it Cross ministry governance includes: 1) Ministry of Health	Taskforce exists and functions with specific responsibility for people with IDD (0.5) Taskforce exists and functions (i.e. has met in the past year) for people with disabilities without any specific responsibility for people with IDD (0.25) Additional 0.5 score if Ministry of Health included No taskforce exists OR the taskforce is not currently functioning (i.e. has not met in the past year) (0)

System Category

1 Governance

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Indicator		Definition	Information required	Scoring methodology
IDD 1.7	National law on capacity and decision-making	Existence of a national law to protect and empower people in healthcare decision-making and informed consent, under which people with IDD are covered (either they are explicitly mentioned or inherently covered)	Yes/No National law includes: 1) Presumption of capacity and guidance to support people to make their own decisions 2) Criteria to assess capacity 3) Protocols and codes of practice to which health professionals must comply when an individual does not have capacity to make their own decisions	National law on capacity and decision-making exists and includes specific reference to people with IDD (0.5) National law on capacity and decision-making exists with no specific reference to people with IDD (0.25) National law meets at least one requirement (0.25) National law meets all three requirements (0.5) No law on capacity and decision-making exists (0)
IDD 1.8	National IDD Clinical Care Standards	National IDD Clinical Care Standards available and monitored by national institution	Yes/No 1) National clinical care standards are available to outline expected service delivery and conditions of service quality of people with IDD 2) Quality of care is monitored by a national institution, such as a Quality Care Commission	National clinical care standards are available for people with IDD (0.5) National clinical care standards are available for people with disabilities in general, without specific reference to people with IDD (0.25) Quality of care is monitored by a national institution (0.5) No National clinical care standards exist (0)
IDD 1.9	National guidance on reasonable accommodation for people with IDD	Guidance on reasonable accommodation for people with IDD is available for national health providers	Yes/No National guidance on reasonable accommodation is available and provide detail on relevant accommodations (such as longer appointments and quiet waiting spaces), informed decision-making, health management and caregiver support	Guidance available on reasonable accommodation for people with IDD (1) Guidance available on reasonable accommodation for people with disabilities in general, without specific reference to people with IDD (0.5) No guidance on reasonable accommodation exists (0)

System Category

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2 Leadership

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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, including designated responsibilities for people with IDD OR a focal point/team in MoH that's responsible for ensuring health access for people with IDD	Yes/No, role/team exists and functions (i.e. has met in the past year), with description of responsibility for IDD inclusion, and title of role/team	Role/team exists and functions with specific responsibilities for people with IDD (1) Role/team exists and functions (i.e. has met in the past year) for people with disabilities, without any specific responsibilities for people with IDD (0.5) No role/team exists OR the role/team is not currently functioning (0)
2.2 National health sector coordinators	Formal representation of persons with IDD and caregivers at highest-level in National health sector	Yes/No, and title of structure/group	Yes (1) No (0)
2.3 Pandemic preparedness structures	Formal representation of people with IDD and caregivers in national taskforce, e.g. COVID-19	Yes/No, and title of structure/group	Yes (1) No (0)

System Category

3 Health financing

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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 and value ($)	Yes, at the federal or decentralized level (1) No (0)
3.2	Reimbursement adjustments	Reimbursement adjustments available for services provided to patients with disabilities, including for services provided to people with IDD specifically (e.g. specialist IDD dentistry or mental health services)	Yes/no For example, there is a national health insurance reimbursement or there is adjusted capitation rates for people with disabilities, including for services provided to people with IDD	Adjustments for people with disabilities, including people with IDD (0.5) Adjustments specifically for services provided to people with IDD (0.5) No adjustments available (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

4 Data & Evidence

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Indicator	Definition	Information required	Scoring methodology
4.1 Maturity of IDD and health data collection	Maturity of IDD and health data collection method	How was IDD and health data gathered? - National census/survey - Healthcare register of people with IDD - Health information records tag people with IDD (electronic integrated system)	Data is collected through health information records tagging people with IDD (1) There is a national register for people with IDD connected to health data (0.67) National survey/census asks IDD questions (0.33) IDD and health data is not collected (0)
4.2 Quality of IDD and health data collection method	Quality of IDD and health data collection method	Quality criteria: 1) Data collection method uses a validated tool (both for assessment of IDD and health outcome measures) 2) Data collection is recent - in the last 10 years 3) Data is nationally representative	Each criteria scores 0.33 points
4.3 Maturity of IDD and health data usage	Maturity of how IDD and health data is used	1) IDD health data that is collected is analysed and published 2) Findings from the data are used to inform program and policy change	Data is analysed and reported and used to direct policy and program change (1) Data is analysed and published (0.5) Data is not analysed and reported (0)
4.4 Quality of IDD and health data usage method	Quality of IDD 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 analysed 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

Service delivery components and indicators

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Missing Billion Inclusive Health Systems Framework

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5 Autonomy and awareness

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Indicator		Definition	Information required	Scoring methodology
5.1	Organisation of Persons with Disability (OPD) advocacy	OPDs (including organisations of caregivers) advocate on the right to health for people with IDD with government and NGO delivery partners	OPDs have been engaged as advisory roles / partnerships with the Ministry of Health AND OPDs have representation of people with IDD and caregivers	Specific IDD OPD engaged (1) General disability OPD with IDD representation engaged (0.67) General disability OPD with no IDD representation engaged (0.33) No OPD engagement (0)
5.2	Autonomy and awareness	People with IDD and caregivers report autonomy and awareness about health access (including knowledge on services available and referral pathways)	If analyzed the following exist: 1) In a quantitative survey (<10 years ago) persons with IDD and caregivers were asked about autonomy and awareness about health (in comparison to people without IDD) OR 2) In qualitative data published (<10 years ago) in a peer-reviewed journal persons with IDD and caregivers reported on autonomy and awareness about health	Quantitative data available or both quantitative/qualitative data available (1) Only qualitative data available (0.5) No data available (0)
5.3	Accessibility of health information	Health information is available in accessible formats for people with IDD and caregivers	Health information is available on the main national health information website regarding healthcare for people with IDD. This should include: 1) Information for people with IDD in accessible formats, meaning simplified information via easy read text, graphic images, video 2) Targeted information for caregivers on supporting people with IDD in health management and accessing healthcare services	Information for people with IDD is available in accessible formats on the national health information website (0.5) Information for caregivers on supporting people with IDD is available on the national health information website (0.5) No information is available for people with IDD and caregivers on the national health information website (0)
IDD 5.4	Supported decision-making and informed consent	People with IDD are supported to make informed decisions about their healthcare	If the following exist: 1) In a quantitative survey (<10 years ago) persons with IDD and caregivers were asked about informed consent and decision making OR 2) In qualitative data published (<10 years ago) in a peer-reviewed journal persons with IDD and caregivers reprted about informed consent and decision making in healthcare	Quantitative data available or both quantitative/qualitative data available (1) Only qualitative data available (0.5) No data is available (0)

Service delivery

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6 Affordability

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Indicator	Definition	Information required	Scoring methodology
6.1 Health coverage	People with IDD 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 covered for all people with IDD / Healthcare is partially covered or for a subset of people with IDD / No % of eligible people with IDD are receiving coverage for free healthcare	All healthcare covered for all people with IDD (1) Healthcare partially covered for all people with IDD OR all healthcare covered for a subset of people with IDD (0.5) No healthcare coverage for people with IDD (0) N/A
6.2 Transport subsidy available for people with IDD	Transport subsidy is available for people with IDD, including travel to medical care	Yes/No Hospital/health centre dedicated services	Yes - there is subsidised transport and facility dedicated services (1) Yes - there is subsidised transport but not facility dedicated services (0.5) No subsidised transport for people with IDD (0)
6.3 Disability allowance	There is a disability allowance that is available to people with IDD to cover healthcare fees not covered by existing insurance or tax-based systems (e.g. assistive technologies)	Yes/No Name, scope and criteria of allowance	There is a disability allowance available to people with IDD (1) There is no disability allowance available for people with IDD (0)
6.4 Co-pays	Any co-pays for services in either health insurance or taxation based systems are waived for persons with IDD	Yes/No	Yes (1) No (0)

7 Human Resources

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Indicator		Definition	Information required	Scoring methodology
7.1	Training of medical doctors	Information about IDD (including core competencies for the care of people with IDD) delivered in medical schools/colleges	Yes/No, and description of whether: - Training content includes information about IDD and health (e.g. causes of IDD, risk of health conditions and health promotion strategies) - Training content includes core competencies in the care of people with IDD (e.g. communication, reasonable accommodation) - The training is part of the national curricula or is delivered as part of the training by some medical schools/colleges	Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the national curricula (1) Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the training or education in at least some medical schools/colleges (0.5) Information about IDD, but without specific mention of core competencies for the care of people with IDD, is delivered as part of the training or education in at least some medical schools/colleges (0.25) Information on IDD is not part of the national curricula or training in any medical schools/colleges (0)
7.2	Training of nurses	Information about IDD (including core competencies for the care of people with IDD) delivered in nursing schools/colleges	Yes/No, and description of whether: - Training content includes information about IDD and health (e.g. causes of IDD, risk of health conditions and health promotion strategies) - Training content includes core competencies in the care of people with IDD (e.g. communication, reasonable accommodation) - The training is part of the national curricula or is delivered as part of the training by some nursing schools/colleges	Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the national curricula (1) Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the training or education in at least some nursing schools/colleges (0.5) Information about IDD, but without specific mention of core competencies for the care of people with IDD, is delivered as part of the training or education in at least some nursing schools/colleges (0.25) Information on IDD is not part of the national curricula or training in any nursing schools/colleges (0)
7.3	Training of CHWs	Information about IDD (including core competencies for the care of people with IDD) delivered in CHW training	Yes/No, and description of whether: - Training content includes information about IDD and health (e.g. causes of IDD, risk of health conditions and health promotion strategies) - Training content includes core competencies in the care of people with IDD (e.g. communication, reasonable accommodation) - The training is part of the national CHW training curricula or is delivered as part of some CHW training programmes	Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the national curricula (1) Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the training or education in at least some CHW training programmes (0.5) Information about IDD, but without specific mention of core competencies for the care of people with IDD, is delivered as part of the training or education in at least some CHW training programmes (0.25) Information on IDD is not part of the national curricula or training in any CHW training programmes (0)
7.4	N/A (in this module)	N/A (in this module)	N/A (in this module)	N/A (in this module)

Service delivery

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7 Human Resources

Indicator		Definition	Information required	Scoring methodology
7.5	Satisfaction	People with IDD and caregivers report that they feel well treated by health workers	If the following exist 1) In a quantitative survey (<10 years ago) persons with IDD and caregivers were asked about satisfaction with health worker services (in comparison to people without IDD) OR 2) In qualitative data published (<10 years ago) in a peer-reviewed journal persons with IDD and caregivers reported about how they feel treated by health workers	Quantitative data available or both quantitative/qualitative data available (1) Only qualitative data available (0.5) No data is available (0)
IDD 7.6	Training of physiotherapists	Information about IDD (including core competencies for the care of people with IDD) delivered in physiotherapist training	Yes/No, and description of whether: - Training content includes information about IDD and health (e.g. causes of IDD, risk of health conditions and health promotion strategies) - Training content includes core competencies in the care of people with IDD (e.g. communication, reasonable accommodation) - The training is part of the national physiotherapist training curricula or is delivered as part of some physiotherapist training programmes	Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the national curricula (1) Information about IDD, including core competencies for the care of people with IDD, is delivered as part of the training or education in at least some physiotherapist training programmes (0.5) Information about IDD, but without specific mention of core competencies for the care of people with IDD, is delivered as part of the training or education in at least some physiotherapist training programmes (0.25) Information on IDD is not part of the national curricula or training in any physiotherapist training programmes (0)
IDD 7.7	Care coordination and support staff	Care coordinators are available to assist people with IDD and caregivers with health access	# care coordination and support staff, including name of role and description of services Responsibilities of these staff should include: 1) Proactively identify people with IDD in local communities that need health support 2) Collaborate with health practitioners to assist people with IDD navigate health and care services 3) Support people with IDD and caregivers to make informed healthcare decisions	Existence of care coordination and support staff - holding at least one of the responsibilities listed (0.5) Information on number of care coordination and support staff available (0.5) No information on care coordination and support staff, including existence and number (0)

Service delivery

MISSING BILLION

8 Health facilities

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Indicator		Definition	Information required	Scoring methodology
8.1	National accessibility standards	Existence of national accessiblity standards for healthcare facilities, including specific provisions for people with IDD, such as accessible information	Yes/No	National accessibility standards available with specific provisions for people with IDD (1) National accessibility standards available without specific provisions for people with IDD (0.5) No National accessibility standards exist (0)
8.2	Accessibility of facilities	Accessibility audit of health facilities has been undertaken in the last 10 years with information collected on accessibility for people with IDD	Yes/No Requirements: 1) They include a measure of accessibility for people with IDD, including accessibility of information provided 2) Results of audit report in published government report/documents or peer-reviewed journal 3) Mandatory/non-mandatory for facilities to meet accessibility standards	Accessibility audit undertaken including information on people with IDD (0.25) Additional requirements 0.25 each No accessibility audit conducted OR no information on people with IDD included in accessibility audit (0)
IDD 8.3	National register available to health professionals	National register/database available to health professionals and service providers on people with IDD, their health needs and their desired reasonable accommodations	Yes/No	Yes (1) No (0)
IDD 8.4	Early childhood screening	All children receive routine developmental screening in years 0-3, including assessment of IDD	% of children screened 1) IDD is assessed in routine developmental screening 2) Children with IDD are referred to relevant services and support	Routine developmental screening provided for all children in years 0-3 (0.33) IDD assessed in this routine screening (0.33) Children with IDD referred to relevant support (0.33) No routine developmental screening provided for children years 0-3 (0)

Service delivery

9 Assistive technology and Rehabilitation

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Indicator	Definition	Information required	Scoring methodology
9.1 National assessments	National Assessment of Assistive Technology or rehabilitation (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	National assessment conducted (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 rehabilitation 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	LMIC: Above 30/1,000,000 population (1) HIC: Above 300/1,000,000 (1) Below the threshold for population (0)

Service delivery

MISSING BILLION

Outputs and outcomes (optional)

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Missing Billion Inclusive Health Systems Framework

Mandatory, scored components				*Optional components*	
System	Service Delivery			Outputs	Outcomes
1 Governance	Demand	5 Autonomy and Awareness		10 Effective Service Coverage	11 Health Status
2 Leadership		6 Affordability			
3 Health Financing	Supply	7 Human Resources			
4 Data & Evidence		8 Health Facilities			
		9 Rehabilitation Services & AT			

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

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10 Effective Service Coverage (optional)

Indicator	Definition	Information required	Scoring methodology
10.1 Modern contraception coverage	Women whose demand is satisfied with a modern method of contraception, disaggregated by IDD	% of women with IDD satisfied compared to women without disabilities	
10.2 ARTs coverage	People with HIV receiving ART, disaggregated by IDD	% of people with IDD that have coverage compared to coverage of people without disabilities	
10.3 COVID-19 vaccine coverage	People who have received the COVID-19 vaccination, disaggregated by IDD	% of people with IDD vaccinated compared to people without disabilities	
10.4 Refractive error coverage	People with refractive error have coverage of glasses	% of people with IDD with need who have glasses (e.g. from RAAB survey)	
10.5 NCD coverage	People with diabetes on treatment OR people with hypertension on treatment, disaggregated by IDD	% of people with IDD on treatment compared to people without disabilities	

Outputs

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11 Health Status (optional)

Indicator		Definition	Information required	Scoring methodology
11.1	Mortality	Overall mortality rate of people with IDD	Deaths per 100 000 population; people with IDD compared to people without disabilities	
11.2	Diabetes	Prevalence of diabetes OR hypertension among persons aged 18+ years, disaggregated by IDD	% of people with IDD with diabetes or hypertension compared to people without disabilities	
11.3	HIV	Prevalence of HIV, disaggregated by IDD	% of people living with HIV among adults aged 15–49; people with IDD compared to people without disabilities	
11.4	Overweight and obesity	Prevalence of overweight and obesity among persons aged 18+ years, disaggregated by IDD	% of people with IDD overweight compared to people without disabilities	
11.5	Wasting	Prevalence of children wasted (moderate and severe), 0-59 months of age, disaggregated by IDD	% of children with IDD wasted compared to children without disabilities	
IDD 11.6	Mental heath conditions	Prevalence of common mental disorders (depression and anxiety), disaggregated by IDD	% of people with IDD with depression or anxiety compared to people without disabilities	

Outcomes

11 Health Status (optional)

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Indicator		Definition	Information required	Scoring methodology
IDD 11.7	Epilepsy	Prevalence of epilepsy, disaggregated by IDD	% of people with IDD with epilepsy compared to people without disabilities	
IDD 11.8	Asthma	Prevalence of asthma, disaggregated by IDD	% of people with IDD with asthma compared to people without disabilities	
IDD 11.9	Dementia	Prevalence of dementia, disaggregated by IDD	% of people with IDD with dementia compared to people without disabilities	
IDD 11.10	Oral health	Prevalence of oral health conditions, disaggregated by IDD	% of people with IDD with oral health conditions compared to people without disabilities	
IDD 11.11	Heart disease	Prevalence of heart disease, disaggregated by IDD	% of people with IDD with heart disease compared to people without disabilities	
IDD 11.12	Hearing loss	Prevalence of hearing loss, disaggregated by IDD	% of people with IDD with hearing loss compared to people without disabilities	

Outcomes

Sample SLA-IDD Module output

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

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

Sample output: SLA-IDD Module output will provide a high-level overview of the system

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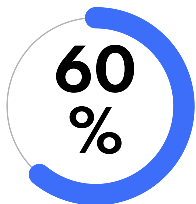
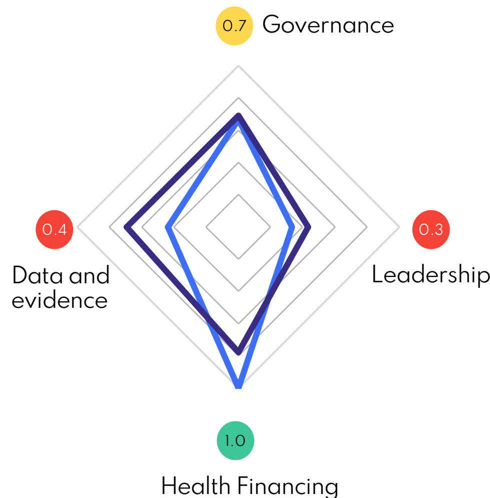
Low (<0.5) Intermediate (0.5-0.74) Advanced (0.75-1) Sample country Comparison countries[2]

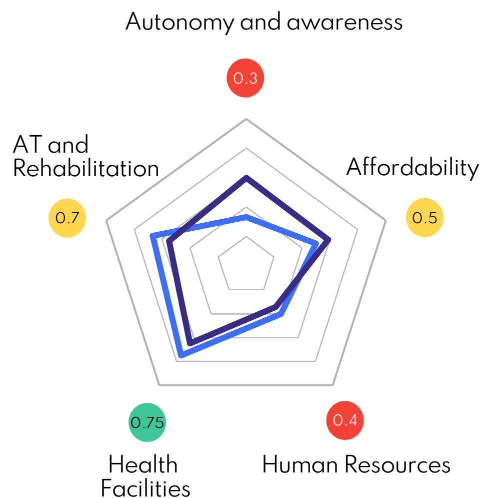
Overall score[1]



System delivery



Service delivery



Key takeaways

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

- **Increasing formal representation of people with IDD/OPDs** in health sector teams
- **Analyzing and publishing datasets within 3 years of collection**, ensuring the data collection and analysis methods are transparent and the publication/raw data 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 including online resources and printed materials

MISSING BILLION

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

Sample output: The SLA-IDD Module provides a breakdown by indicator

Special Olympics Health
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● Low (<0.5) ● Intermediate (0.5-0.74) ● Advanced (0.75-1)

1 Governance		Score
1.1	Ratification and adoptions of UN Convention on the Rights of Persons with Disabilities (CRPD)	Intermediate
1.2	Existence of a national law protecting the right to health for persons with disabilities, with specific reference for people with IDD OR an independent national law protecting the right to health for people with IDD	Low
1.3	Existence of a national policy or decree on health for persons with disabilities, with specific reference for people with IDD OR an independent national policy or decree on health for people with IDD	Low
1.4	Inclusion of people with disabilities in National Health Sector Plan(s) led by the national health regulator, with specific reference for people with IDD OR there is an independent National Health Sector Plan for people with IDD led by the national health regulator	Low
1.5	Inclusion of people with disabilities in National disease plan (e.g., HIV, rare diseases, hepatitis), with specific reference to the needs of people with IDD	Low
1.6	Cross-ministry taskforce or structure to coordinate work on disability inclusion, including specific responsibility for people with IDD	Intermediate
IDD 1.7	Existence of a national law to protect and empower people in healthcare decision-making and informed consent, under which people with IDD are covered (either they are explicitly mentioned or inherently covered)	Low
IDD 1.8	National IDD Clinical Care Standards available and monitored by national institution	Intermediate
IDD 1.9	Guidance on reasonable accommodation for people with IDD is available for national health providers	Low

2 Leadership		Score
2.1	Existence of a focal point/team in MoH that's responsible for ensuring health access for people with disabilities, including designated responsibilities for people with IDD OR a focal point/team in MoH that's responsible for ensuring health access for people with IDD	Low
2.2	Formal representation of persons with IDD and caregivers at highest-level in National health sector	Low
2.3	Formal representation of people with IDD and caregivers in national taskforce, e.g. COVID-19	Low

3 Health Financing		Score
3.1	Budget (MoH or devolved levels) for role/department in MoH working on disability inclusion	Low
3.2	Reimbursement adjustments available for services provided to patients with disabilities, including for services provided to people with IDD specifically (e.g. specialist IDD dentistry or mental health services)	Low
3.3	Funding for AT/rehabilitation in MoH (or devolved levels) budget	Low

MISSING BILLION

Sample output: The SLA-IDD Module provides a breakdown by indicator

Special Olympics Health
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● Low (<0.5) ● Intermediate (0.5-0.74) ● Advanced (0.75-1)

4 Data and evidence		Score
4.1	Maturity of IDD and health data collection method	Intermediate (yellow)
4.2	Quality of IDD and health data collection method	Low (red)
4.3	Maturity of how IDD and health data is used	Low (red)
4.4	Quality of IDD and health data usage method	Low (red)

5 Autonomy and awareness		Score
5.1	OPDs (including organisations of caregivers) advocate on the right to health for people with IDD with government and NGO delivery partners	Low (red)
5.2	People with IDD and caregivers report autonomy and awareness about health access (including knowledge on services available and referral pathways)	Low (red)
5.3	Health information is available in accessible formats for people with IDD and caregivers	Intermediate (yellow)
IDD 5.4	People with IDD are supported to make informed decisions about their healthcare	Low (red)

6 Affordability		Score
6.1	People with IDD are fully covered for free healthcare through social health insurance, tax-based system, provision as part of disability allowance or any other stipulations	Intermediate (yellow)
6.2	Transport subsidy is available for people with IDD, including travel to medical care	Intermediate (yellow)
6.3	There is a disability allowance that is available to people with IDD to cover healthcare fees not covered by existing insurance or tax-based systems (e.g. assistive technologies)	Intermediate (yellow)
6.4	Any co-pays for services in either health insurance or taxation based systems are waived for persons with IDD	Low (red)

Sample output: The SLA-IDD Module provides a breakdown by indicator

Special Olympics Health
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Low (<0.5) Intermediate (0.5-0.74) Advanced (0.75-1)

7 Human Resources	Score
7.1 Information about IDD (including core competencies for the care of people with IDD) delivered in medical schools/colleges	Low
7.2 Information about IDD (including core competencies for the care of people with IDD) delivered in nursing schools/colleges	Low
7.3 Information about IDD (including core competencies for the care of people with IDD) delivered in CHW training	Low
7.5 People with IDD and caregivers report that they feel well treated by health workers	Low
IDD 7.6 Information about IDD (including core competencies for the care of people with IDD) delivered in physiotherapist training	Low
IDD 7.7 Care coordinators are available to assist people with IDD and caregivers with health access	Low

8 Health facilities	Score
8.1 Existence of national accessiblity standards for healthcare facilities, including specific provisions for people with IDD, such as accessible information	Low
8.2 Accessibility audit of health facilities has been undertaken in the last 10 years with information collected on accessibility for people with IDD	Low
IDD 8.3 National register/database available to health professionals and service providers on people with IDD, their health needs and their desired reasonable accommodations	Low
IDD 8.4 All children receive routine developmental screening in years 0-3, including assessment of IDD	Low

9 Assistive technology and Rehabilitation	Score
9.1 National Assessment of Assistive Technology or rehabiliation (e.g., STAR or RATA) done in the last 10 years	Low
9.2 Coordination mechanism cross-Ministry for rehabiliation services and AT where more than 1 ministries involved	Low
9.3 Physiotherapists available and trained to provide rehabilitation services and assistive technology	Low

MISSING BILLION

Sample output: The SLA-IDD Module provides a breakdown by indicator

Special Olympics Health
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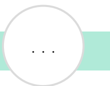
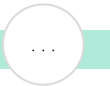
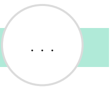
Low (<0.5) Intermediate (0.5-0.74) Advanced (0.75-1)

10 Effective Service Coverage		Score
10.1 Women whose demand is satisfied with a modern method of contraception, disaggregated by IDD		
10.2 People with HIV receiving ART, disaggregated by IDD		
10.3 People who have received the COVID-19 vaccination, disaggregated by IDD		
10.4 People with refractive error have coverage of glasses		
10.5 People with diabetes on treatment OR people with hypertension on treatment, disaggregated by IDD		
11 Health status		
11.1 Overall mortality rate of people with IDD		
11.2 Prevalence of diabetes OR hypertension among persons aged 18+ years, disaggregated by IDD		
11.3 Prevalence of HIV, disaggregated by IDD		
11.4 Prevalence of overweight and obesity among persons aged 18+ years, disaggregated by IDD		
11.5 Prevalence of children wasted (moderate and severe), 0-59 months of age, disaggregated by IDD		

11 Health Status		Score
IDD 11.6 Prevalence of common mental disorders (depression and anxiety), disaggregated by IDD		
IDD 11.7 Prevalence of epilepsy, disaggregated by IDD		
IDD 11.8 Prevalence of asthma, disaggregated by IDD		
IDD 11.9 Prevalence of dementia, disaggregated by IDD		
IDD 11.10 Prevalence of oral health conditions, disaggregated by IDD		
IDD 11.11 Prevalence of heart disease, disaggregated by IDD		
IDD 11.12 Prevalence of hearing loss, disaggregated by IDD		

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

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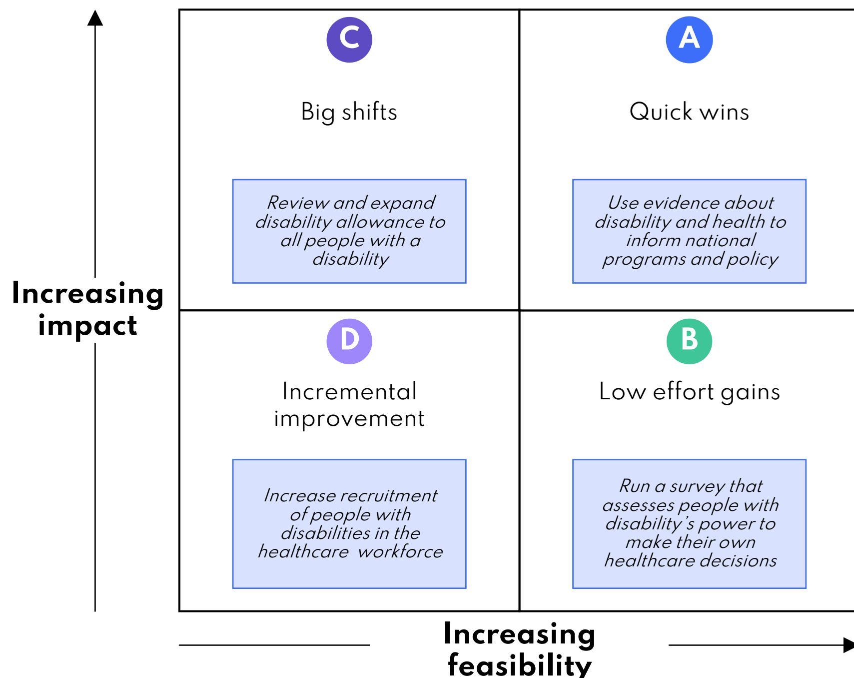
Prioritization matrix, *examples of interventions*



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

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Potential sources of data to inform assessment

- 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, e.g. websites of OPDs

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

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How to work with us

If you are interested in applying The Missing Billion System Level Assessment - IDD module, 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 IDD module**, 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 Missing Billion Initiative **by providing**:

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

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