



# Summary of Key Inputs and Challenges for the UNCT Data Strategy & Potential Pathways for a Use-Case Approach to Support Disability Data





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## I. Background

This document, prepared by Saraswati for the UNCT in Indonesia, outlines underlying factors, inputs and assumptions as a basis to suggest short-term action items focused on disability data for the SDG Data and MEL Working Group to consider in progressing the UNCT's agenda linked to the global data strategy initiated by the UN Secretary General.

In recommending these action items on disability data, we refer principally to the following—each of which is outlined in summary below:

- UN Secretary General's "Data Strategy for Action by Everyone, Everywhere"
- UN Office of the High Commissioner for Human Rights' Guidance Note identifying six principles for a human rights-based approach to data collection
- UNCT Indonesia Data Priorities
- Key External (non-UN) Stakeholder Expectations for the UNCT on Data
- The Situational Analysis on Data in Indonesia and Disability Data research conducted for the UNCT by Saraswati from December 2020-April 2021

### UN Secretary General's "Data Strategy for Action by Everyone, Everywhere"

In April 2021, following a presentation and discussion with UN agency heads in Indonesia on the global data strategy initiated by the UN Secretary General, Pulse Lab Jakarta issued an internal discussion note that summarized key underlying issues from this strategy for the UNCT Indonesia country data strategy as follows:

- *The UN Secretary General has launched a whole of UN data strategy, envisaging that: "...building a whole-of-UN data ecosystem that maximizes the value of our data, we unlock our potential: Better decisions and stronger support to people and planet – in the moments that matter most."*
- *The SG's data strategy highlights disparities of capacity and culture required to undertake the data-driven transformation, and this must be addressed in order to increase the impact and relevance of the UN overall;*
- *The SG's data strategy encourages **use-case centric approaches** <emphasis added> for UN's data-driven transformation". This means undertaking initiatives or pilots which have a clear use or target, and using these initiatives to actually add value to*

*development and advocacy efforts while also learning critical capabilities in terms of analytics<sup>1</sup>, and data management<sup>2</sup>;*

## UNCT Data Priorities

A summary from the UNCT Indonesia retreat in February 2021 highlighted the following:

*“The central focus was on the concept of Leaving No One Behind (LNOB) and how the UN can use this concept in all its aspects of its work ranging from Communications, Programming, Resource Mobilization, Advocacy, Partnerships among others. The conclusion drawn by the UNCT members was that for the LNOB concept to be the driver behind the implementation of the UNSDCF (2021-2025) there is a need to have a UN Data Strategy in place that helps to:*

- *understand which groups are being left behind (historically, structurally, as a result of COVID)*
- *understand the data availability and data gaps within and outside the UN*
- *identify capacity building needs to establish a data and evidence driven culture within the UN, including the role of the Data, M&E and Learning (DMEL) Working Group*
- *understand the partnership opportunities for the UN (within the UN, Government, CSOs, Universities, Think Tanks) to obtain all data needed for evidence-based policy dialogue.”*

## Human Rights-Based Approach to Data Collection

In April 2016, The UN Office of the High Commissioner for Human Rights (OHCHR) issued a guidance note titled ‘*A Human Rights-Based Approach to Data: Leaving No One Behind in the 2030 Development Agenda*’ identifying six principles for a [human rights-based approach to data collection](#), to support monitoring of progress towards the Sustainable Development Goals (SDGs). These six principles are:

- participation in the data collection process, especially by the marginalized
- data disaggregation to guard against discrimination based on sex, age, ethnicity, disability, sexual orientation or religion
- self-identification that does not reinforce further discrimination against vulnerable groups
- transparency regarding the data collection process
- privacy of respondents and maintaining confidentiality of their personal data
- accountability in data collection and use

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<sup>1</sup> Analytics - using data to understand what happened, why it happened, what may happen next, and how to respond

<sup>2</sup> Data Management - ensuring everyone can discover, access, integrate and share the data they need

## Key External (non-UN) Stakeholder Expectations About UN Data Support in Indonesia

At the broadest level, key data stakeholders want from the UN what the UN has identified as the priority within its own global data strategy, namely “*systematic action...to build the necessary capabilities and enablers so that data thrives.*”

Specific suggestions for the UNCT from stakeholders interviewed by Saraswati in support of the Situational Analysis on Data in Indonesia include the following:

### ***Increasingly look beyond data dashboards***

The concern among stakeholders is that interest in dashboard development as *an objective* could distract from addressing more critical data challenges—namely improving data quality, producing and better integrating the most appropriate data, and strengthening the means to understand and plan around these. One area for more systematic attention that overlays all of these challenges could be in identifying incentives to motivate government departments to better share administrative and other data.

### ***Support data integration***

Data interoperability is one of the important goals of the Government of Indonesia’s *Satu Data* (One Data) initiative. The UN could engage key ministries, such as the Ministry of Health, to facilitate integration of data managed under a variety of internal ministry systems and applications, such as the system for TB, Malaria, HIV/AIDS, and others. While greater integration of the most significant source of survey and administrative data, such as BPS and Riskesdas, would be ideal, there would be significant bureaucratic and financial obstacles to progress in this area.

### ***Enable local governments***

There is broad agreement that logistical, capacity, bureaucratic, and resourcing constraints at the subnational government level present significant challenges to data production and analysis. Stakeholders express interest in seeing the UN play a more active role in supporting data knowledge and awareness across subnational governments as well as efforts to enable local governments to better collect important data and participate more actively in the data ecosystem. This could be in partnership with local institutions—such as NGOs, DPOs to promote inclusive data, and universities—that have strong and established relationships with subnational governments.

### ***Identify and support data and statistics training needs skills among relevant stakeholders***

The UN should continue to explore opportunities to encourage the growth in specialized human resources to deal with data at the local and national levels, consistent with the UN Global Data Strategy’s focus on building new capabilities in analytics and data management. While the focus of capacity building could be with national and subnational government departments directed by relevant UN agencies, such as UNICEF (with Kemenko PMK) and UNFPA (with the Directorate of Population and Civil Registration at the Ministry of Home Affairs), development of the capacity of a broader range of stakeholders, including research centers and civil society organizations, on the use of data would promote data utilization and

support a community of practice that could more continuously identify key data challenges and opportunities for support. As important is developing the conceptual capacity of key stakeholders on inclusivity, data disaggregation and why/how these matter to promote LNOB principles in development. Overall, improved data utilisation could lead to stronger problem analysis to determine what needs to be undertaken/advocated and resourced, and also allows for stronger accountability in providing a stronger evidence basis to prove the results of interventions.

***Provide technical expertise to help identify and support key areas of SDG data collection***

Examples offered of important niche areas where UN assistance in support of SDG data could have impact include development of a survey on children with disability and continuing to provide assistance on data collection instruments and methods, for example support to BPS in developing Small Area Estimation (SAE) methods to provide data estimates at the local level. At a broader level, the UN could support the BPS and/or line ministries to explore the most viable means to adapt global indicators in the Indonesian context, since some global indicators have not yet been adopted. As the custodian of SDG data, the UN could also demonstrate stronger commitment to adopt inclusive data collection in its development programming and ensure that disaggregated data, including disability data and intersectionality, are sufficiently reflected in its program monitoring frameworks as evidence of data advocacy.

***Promote partnerships by more actively leveraging the UN's convening authority***

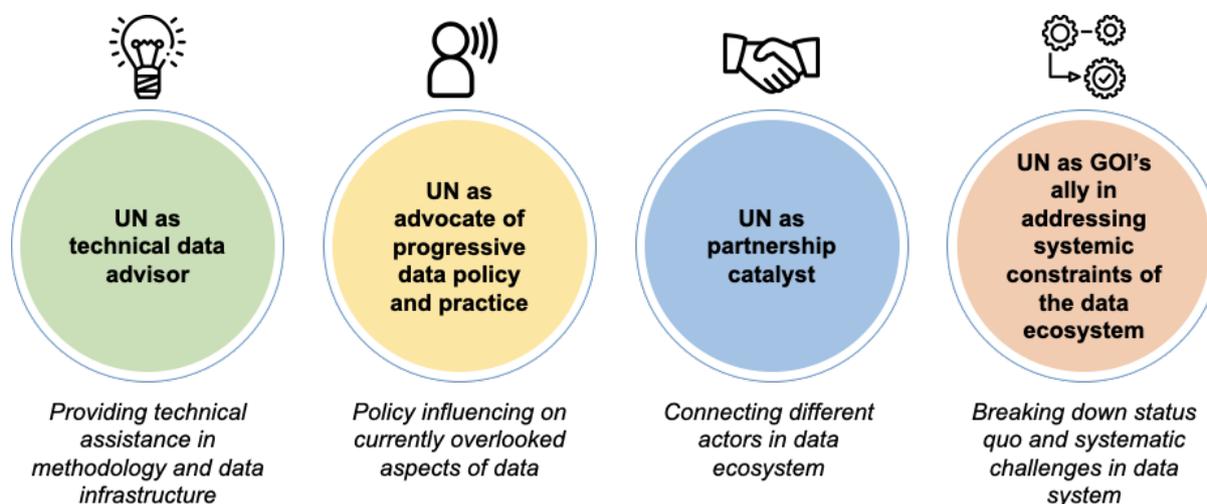
The UN occupies a unique position in having the incentive and authority to convene key stakeholders—from the Government of Indonesia to civil society organizations and other development partners—to promote achievement of the SDGs. Stakeholders welcome the UN employing this convening authority in a more focused, proactive and systematic way to identify key data gaps and means to address these while also coordinating assistance through mapping who is doing what to support key data objectives in support of the SDGs. The UN could map stakeholders according to the extent that they are working with core GOI institutions on the most critical data issues in order to support planning and evaluation of Indonesia's development initiatives. Strategic decisions then need to be made on strengthening key relationships and which priority issues need to be advocated collectively.

***Help define and support the most appropriate role for civil society organizations (CSOs) as data actors in support of the SDGs***

CSOs are cited as important providers of data—as well as providers of information on sources of data for SDG indicator estimation—in UN materials, including meeting minutes from the DfSDG working group. However, in practice, there are significant questions about CSO capacities and incentives for producing data that is routine and sustainable enough as well as of high enough quality to be endorsed by the BPS and other data experts. The UN could support identification of key CSO data partners, as well as engage with other development partners to explore how to support these partners to be more effective data actors in support of SDG data production. In doing so, the UN could promote the importance of data sharing and increase broader stakeholder interest in engaging around data for the purpose of SDG reporting and informed policy making.

## Proposed Pathways for the UNCT, Deriving from the Situational Analysis

Different challenges require different pathways: the wide range of data challenges identified in the Situational Analysis conducted by Saraswati call for a number of roles which the UN could potentially play. We propose four broad pathways:



<b>Proposed pathways</b>	<b>Potential action points</b>
 <p>UN as technical data advisor</p>	<ul style="list-style-type: none"> <li>• Supporting the GOI in improving administrative data systems, data collection methods, data quality assurance mechanisms</li> <li>• Identifying and supporting data and statistics training needs skills</li> <li>• Filling in data gaps by advising the GOI on how to collect data effectively, including how to best adopt currently unmeasured SDGs indicators</li> <li>• Assisting GOI in exploring novel utilization of data, including geospatial data</li> <li>• Facilitating knowledge transfer of methods or technology used at the global level</li> <li>• Extending funding support for enhanced data infrastructure</li> <li>• Providing capacity building to national and sub-national governments on implementing data standardization according to Satu Data standards</li> </ul>
 <p>UN as advocate of progressive data policy and practice</p>	<ul style="list-style-type: none"> <li>• Advocating the significance of currently overlooked data, such as migration/data on migrants, disability, and others. This include promoting the importance of disaggregated data based on <i>Leave No One Behind</i> principles and incorporating marginalized communities in the sampling design</li> <li>• Influencing policy at the highest level to improve data collection, management, disaggregation, and dissemination</li> <li>• Prioritizing data integration and interoperability over creation of new dashboards or applications</li> </ul>

	<ul style="list-style-type: none"> <li>• Promoting the principles of open data and balancing data accessibility with data privacy</li> <li>• Encouraging the GOI to continue to seek out-of-the-box cross-institution data utilization</li> </ul>
 <p>UN as partnership catalyst</p>	<ul style="list-style-type: none"> <li>• Connecting GOI agencies at national and sub-national levels to promote data sharing and interoperability</li> <li>• Promoting private sector involvement in the GOI's data ecosystem</li> <li>• Convening discussions between the GOI and civil society organizations in improving GOI data utilization by the public and promoting data availability for wider audiences</li> <li>• Helping define and support the most appropriate role for civil society organizations as data actors in support of data production</li> <li>• Providing examples of best practices of the involvement of non-state actors in supporting the government's data production or utilization processes</li> </ul>
 <p>UN as GOI's ally in addressing systemic constraints in the data ecosystem</p>	<ul style="list-style-type: none"> <li>• Communicating the systematic issues which exist in data ecosystem to the GOI and co-creating strategies to address key problems</li> <li>• Enabling local governments not only in terms of capacity but also in addressing data issues exacerbated by decentralization</li> <li>• Supporting the GOI in designing strategic data planning and resource allocation to avoid excessive and redundant data collection processes across institutions</li> <li>• Working with multiple substantive experts internally (across UN agencies) in better coordinating UN responses to tackling cross-sector issues</li> </ul>

## Key Challenges Identified in the Situational Analysis & Disability Data Report

### Key challenges (Situational Analysis)

- Low availability and accessibility of data for relevant stakeholders
- Limited data utilization → limited resources, creativity, and knowledge, especially at the subnational government level
- Absence of standardized strong quality assurance mechanisms across all data
- Inseparability between data and the political economy context
- Lack of data standardization
- Ineffective resource allocation for data management
- Limited data disaggregation

### Key challenges (Disability Data report)

- The different mandates among GOI agencies and resulting lack of data integration
- Different disability definitions and methodologies used in data collection by different institutions result in wasted resources, as well as limited data accuracy and comparability

- Disability issues are yet to be fully understood within the GOI, which is reflected in what data the GOI currently collects, how it is collected and the lack of availability of crucial data
- The self-identification and prone-to-stigma nature of disability data collection
- Exclusion of people with disability from data collection
- Limited disaggregation
- Limited evidence of data utilisation and quality assurance

# Summary

UNCT Strategic Priorities	Key Actions	Approach	Key Challenges
<ul style="list-style-type: none"> <li>● Focus on the concept of Leaving No One Behind (LNOB) and how the UN can use this concept in all its aspects of its work ranging from Communications, Programming, Resource Mobilization, Advocacy, Partnerships among others</li> <li>● Build on on-going initiatives and commitments made to the GOI, which includes support for the GOI-managed SDG dashboard through strengthening coordination mechanisms to ensure data availability (including disaggregation by LNOB, including disability), data quality assurance mechanisms, and data utilization</li> <li>● Respond to specific in-country needs, which include: support for effective implementation of the GOI's <i>Satu Data</i> (One Data) initiative; better identification of groups vulnerable to climate action and the COVID-19 pandemic; and improvements in social protection data</li> </ul>	<ul style="list-style-type: none"> <li>● Identify which groups are being left behind (historically, structurally, as a result of COVID 19 and climate change)</li> <li>● Leverage convening authority to identify and map data availability and data gaps within and outside the UN</li> <li>● Clarify the key policy/development challenges—as well as SDG priority needs—that need to be addressed</li> <li>● Identify capacity building needs and organizational challenges to establish a data and evidence driven culture within the UN</li> <li>● Identify partnership opportunities to promote more relevant and higher quality data, availability of these data and <i>connection of these data</i> needed for evidence-based policy dialogue and SDG monitoring through joint assessments and analysis. This should include maintenance of a data inventory and development of data access strategies.</li> <li>● Discuss findings and implications; promote action</li> </ul>	<ul style="list-style-type: none"> <li>● Use-case centric approach (reference: <i>UN global data strategy</i>)</li> <li>● Support data knowledge, availability, integration, quality and utilization at the national and subnational levels (reference: <i>Situational Analysis</i>)</li> <li>● Apply the human rights-based approach to data collection (reference: <i>UHCHR</i>):             <ul style="list-style-type: none"> <li>- <i>participation in the data collection process, especially by the marginalized</i></li> <li>- <i>data disaggregation to guard against discrimination based on sex, age, ethnicity, disability, sexual orientation or religion</i></li> <li>- <i>self-identification that does not reinforce further discrimination against vulnerable groups</i></li> <li>- <i>transparency regarding the data collection process</i></li> <li>- <i>privacy of respondents and maintaining confidentiality of their personal data</i></li> <li>- <i>accountability in data collection and use (for example, through regular inclusive learning and progress updates)</i></li> </ul> </li> </ul>	<p>Disparities of capacity and culture—within the UN and among key stakeholders—required to undertake data-driven transformation</p> <p>Limited data disaggregation</p> <p>Low availability and accessibility of data for relevant stakeholders</p> <p>Lack of data standardization</p> <p>Different mandates among GOI agencies and resulting lack of data integration</p> <p>Limited data utilization → limited resources, creativity, and knowledge, especially at the subnational government level</p> <p>Absence of standardized strong quality assurance mechanisms across all data</p> <p>Inseparability between data and the political economy context</p> <p>Ineffective resource allocation for data management</p> <p>Disability issues are yet to be fully understood within the GOI, which is reflected in what data the GOI currently collects, how it is collected and the lack of availability of crucial data</p> <p>The self-identification and prone-to-stigma nature of disability data collection</p> <p>Exclusion of people with disability from data collection</p>

## II. Proposed Action Steps on Disability Data

### Rationale for Focusing on Disability Data as a Short-term Priority

An initial focus on disability data for the use-case approach in support of the UNCT Indonesia data strategy has been proposed for the following reasons:

- Promoting disability data addresses LNOB priorities
- Disability data is cross-cutting and, therefore, relevant across UN work in Indonesia
- The disability data report commissioned by the UNCT and produced by Saraswati was a response to the UNCT prioritizing the importance of disability data and identified clear gaps and needs

### Recommendations

In outlining the problem-driven pathways that need to be taken to design and implement a use-case focusing on disability data, this report takes three elements into consideration: i) the gaps that needs to be addressed, ii) expectations from the GOI and other actors on the UN's role, and iii) the internal capacity as well as strategic priorities of the UN—both globally and in Indonesia—to take on opportunities.

#### Step-by-step recommendations to develop Disability Data use-case

- I. **Define and agree upon the definition of disability that will consistently be used and advocated by the UNCT and throughout the use-case process.** Disability is an evolving concept even though it is globally accepted that disability is a result from the interaction between persons with impairments and environmental barriers. While Indonesia has adopted the statutory definition of the UNCRPD's disability definition, there are inconsistencies and discrepancies in translation of disability concepts in practice, especially relating to disability data collection. Different disability definitions and deviation in methodologies of data collection and its instruments by different institutions has resulted in limited accuracy and comparability. Identification of inconsistencies, where these take place and why, what the implications are and using this analysis to refine advocacy strategies will be an important start.
- II. **Develop a set of research or policy questions that the UNCT should answer regarding disability data in relation to the SDGs.** Consultation with DPO representatives and disability experts suggest the following initial research questions (and exploration of how well positioned the UNCT is to respond to each of these questions):
  - a. Who is "left behind" and why?
  - b. What should be done to address these challenges?
  - c. To what extent are disability data available and used to answer the main goals of why these data are collected?
  - d. How might existing data be more effectively used to measure achievement and progress?

- e. How accountable is the UNCT towards disability and other at risk communities? What mechanisms are in place to advance accountability?
- f. How might the UN strengthen and effectively implement meaningful participation of disability groups in its project/program cycle management?
- g. How well are the UN and its implementing partners ensuring the availability of disability data and information in their development programs?
- h. How have disability data and information been used to inform/ influence the UN's programs and support to the government and its development partners?

III. **Identify gaps as well as specific aspects and issues to advocate effectively to make an impact relating to disability.** Disability data research has identified issues and gaps of the current disability data. To be able to advocate effectively and make an impact relating to disability, priorities have to be established and advocacy strategies have to be developed collaboratively with the most important stakeholders, which are people with disabilities and DPOs. Some critical gaps raised by DPOs are:

- a. availability and access to disability data/information by DPOs and PWDs to enable local verification (e.g. initiatives like pedulilindungi.id may be adopted for disability data)
- b. weak coordination, limited utilisation and siloed ways of working of disability data management by different stakeholders. Key actors to be approached as targets for advocacy include BAPPENAS, Coordinating Ministries, MoSA, and BPS. Positioning MoSA as the technical ministry for disability data is problematic as it will confine and limit the scope of disability as a mere social welfare issue rather than a cross-cutting issue. To address this issue and advocate disability as a cross-cutting issue, BAPPENAS is in the most strategic position being the primary responsible body for disability, including disability data, and has the authority to coordinate relevant technical ministries accordingly
- c. DPOs have not been involved in or consulted by the UN in the conceptualisation of the One Data System including its RACI
- d. the absence of a disability data roadmap as a reference for government and other stakeholders from national to local levels
- e. the upcoming National/Regional Action Plan (RAN/RAD) on Disability (currently under development) will have 24 items of policies to be translated into action plans which will require operational guidelines. The guidelines are expected to inform clear mechanisms to connect these plans with the national and regional development plans
- f. the absence of comparative studies and references for Indonesia to learn from other countries that have successfully developed and integrated disability data systems into the country's development program

IV. **Identify key stakeholders in the disability data ecosystem, including their interests, incentives and roles.** Drawing upon the findings of disability data research, further work to deep dive stakeholders and their interests/incentives in disability data could benefit the UNCT in developing advocacy strategies for

disability and LNOB. Identification of who among the UN agencies has data agreements and with which ministries and or other partners (such as the private sector) will be important to identify the starting point.

V. **Collect learning and evidence that can be used for advocacy for improved disability data.** Pre-existing sources of data can be considered for disability data analysis, such as:

- a. the government's disability data and information (e.g. census, SUSENAS, etc.) and sectoral data from technical ministries such as Kemendesa, Kemenaker, Kemendikbud
- b. Implementation data from the UN and its implementing partners, including program monitoring and evaluation data that reflects and analyses the situation for PWDs
- c. Studies and research from various stakeholders (including universities, research institutions, and CSOs) and development programs/initiatives (such as PEDULI and TNP2K)
- d. Primary information from PWDs and DPOs

VI. **Engage, consult, and build partnerships with key disability data stakeholders--especially DPOs.**

- a. Engagement and partnerships with DPOs. Evidence suggests the most effective model for influencing and capacity building on disability issues is by promoting facilitated, by-design interactions of various stakeholders with PWDs/DPOs. Designated interactions will help raise awareness and capacity of stakeholders relating to their respective SDGs that include what disability data are needed, as well as how to collect, analyse and utilise these data for measuring SDG achievement and inequalities facing PWDs. Engagement and partnership with DPOs can also address the needs of capacity building, especially to change perspectives and paradigms amongst public officials and policy makers towards disability. Implementation of disability data policies are still challenging because the legal and regulatory framework on disability does not simultaneously provide capacity building to change and transform stakeholders' understanding, perspectives, and paradigms on disability
- b. Develop feedback mechanisms to allow greater participation of and benefit for PWDs. The UNCT could:
  - i. Organise learning forums on disability data development initiatives. Disability coordination platforms such as **Temu Inklusi** could be used as a strategic forum to share information, as well as findings of related studies/research on disability and networking
  - ii. Design appropriate communication strategies for diverse audiences, including PWDs, with inclusive media communication
  - iii. Hold facilitated meetings or interactions that are accessible for PWDs to equally participate in the discussions or decision making
  - iv. Facilitate and ensure participation and engagement of DPOs in reporting and verification of disability data at the local level. One practical example includes the current initiative on the COVID-19

vaccination registration information system, pedulilindungi.id, which could be used as a reference to be adopted for a PWD verification system

- v. Allocate resources to pilot an initiative on *Disabilitas dalam Angka* (Disability in Figures) for key stakeholders at the subnational and national levels with participation by and contributions from the DPO network. The pilot initiative could be implemented for select regions whose governments have a strong commitment and capacity to implement and trial disability data collection initiatives. Potential regions to be considered include former PEDULI program areas such as Sorong (West Papua) and West Lombok (NTB).

**VII. Jointly identify and implement solutions for key disability data challenges with the meaningful participation of people with disability.** To identify

solutions that work, the UN could:

- a. Develop piloting or prototype of disability data collection as a collaborative initiative with DPOs and CSOs. Existing evidence and good practices at the local level can be used for advocacy and replication—for example, PEDULI’s policy recommendations on inclusive civil registration involving DPOs and CSOs (such as Yakkum, SIGAB, and PATTIRO)
- b. Nurture stronger commitment among various stakeholders and develop a roadmap on disability data that includes stakeholder mapping. RAN-RAD can be an entry point for disability data advocacy
- c. Leverage the UN’s influencing authority to advocate disability as a cross-cutting issue to key national and local government stakeholders. This advocacy agenda could include facilitating partnerships among key actors in disability issues such as BAPPENAS, Coordinating Ministries, DPO networks, disability advocacy activists, universities, KND (National Disability Committee), the Human Rights Commission, and the KPK. BAPPENAS should be the main target for disability advocacy
- d. Facilitate dissemination of local learning to promote disability data decentralisation and disability-friendly services through inclusive village development planning processes such as disability-focused village development planning (*musdes*), allocating village funds for the provision of disability-friendly basic services, and adopting disability rights indicators as a reference in planning and monitoring development programs. Other learning that could be promoted includes the recent progressive achievement of disability advocacy for justice (the judicial review led by LBH and SIGAB’s paralegal initiative), which has been more effective compared to lengthy advocacy for PWD rights to education, employment, and health
- e. Advancing advocacy to implement disability rights indicators that also provides operational guidelines and monitoring tools. These indicators have been developed and adopted by local governments, and supplemented with simulation modules for government officials including respective indicators for structure/program, process, and impact

VIII. **Implement capacity building within the UN and for key stakeholders and build partnerships with Disability Networks to jointly formulate short-term priority actions** with reference to the activities mentioned above. This will require more comprehensive assessment by the UN on related capacity strengths and needs as well as on institutional challenges relating to disability awareness and inclusivity as well as the UN's data and evidence-driven culture.

