

Session 3: Planning data collection on disability – general considerations

KEY CONSIDERATIONS FOR STRENGTHENING THE NATIONAL  
STATISTICAL SYSTEM FOR EFFICIENT PRODUCTION OF DISABILITY  
DATA THAT IS RESPONSIVE TO  
NATIONAL POLICY NEEDS AND PRIORITIES

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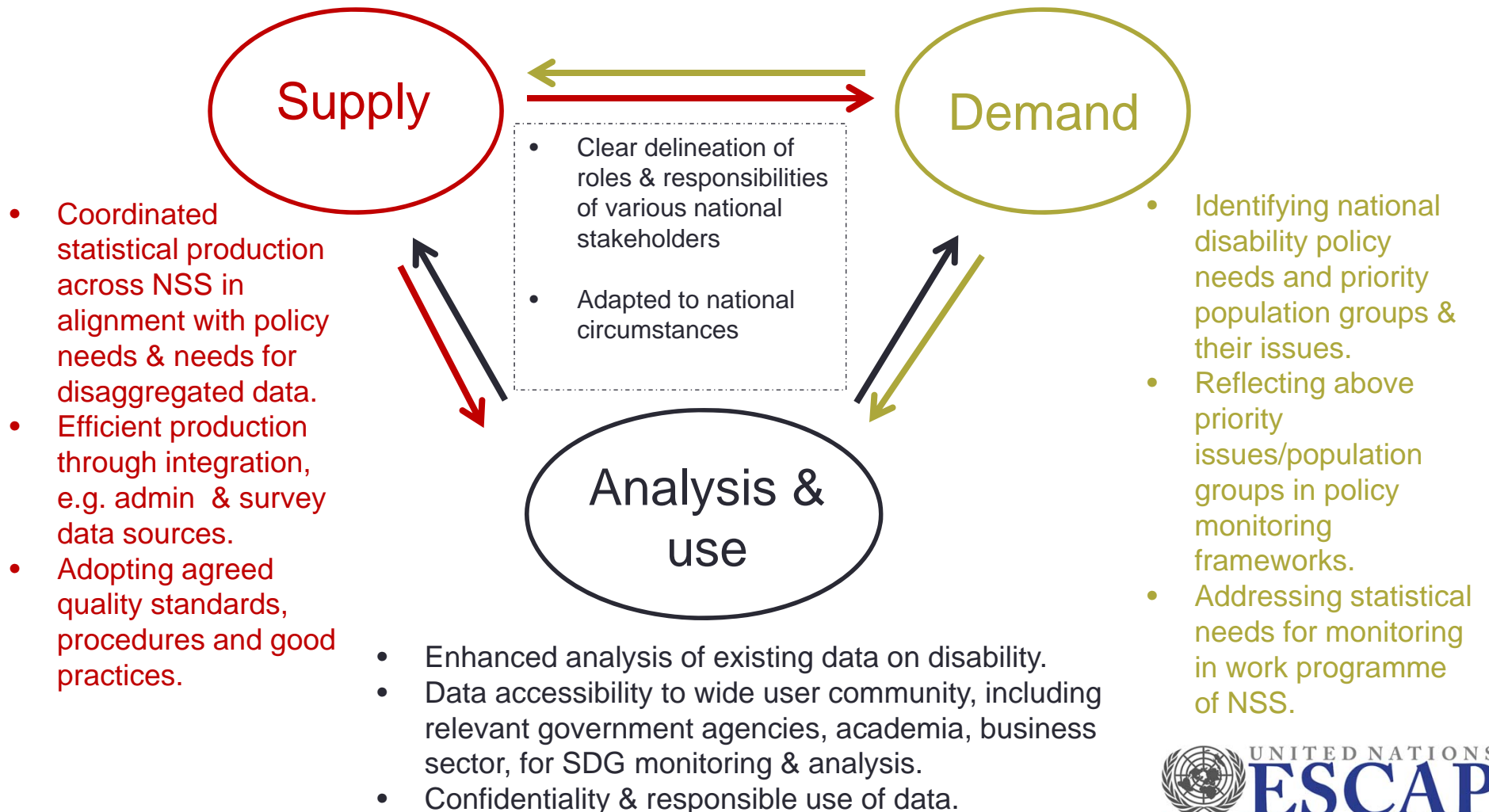
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*Expert Group Meeting on the Guidelines and Principles for the Development of Disability Statistics,  
12-14 July 2017, New York*

# Outline

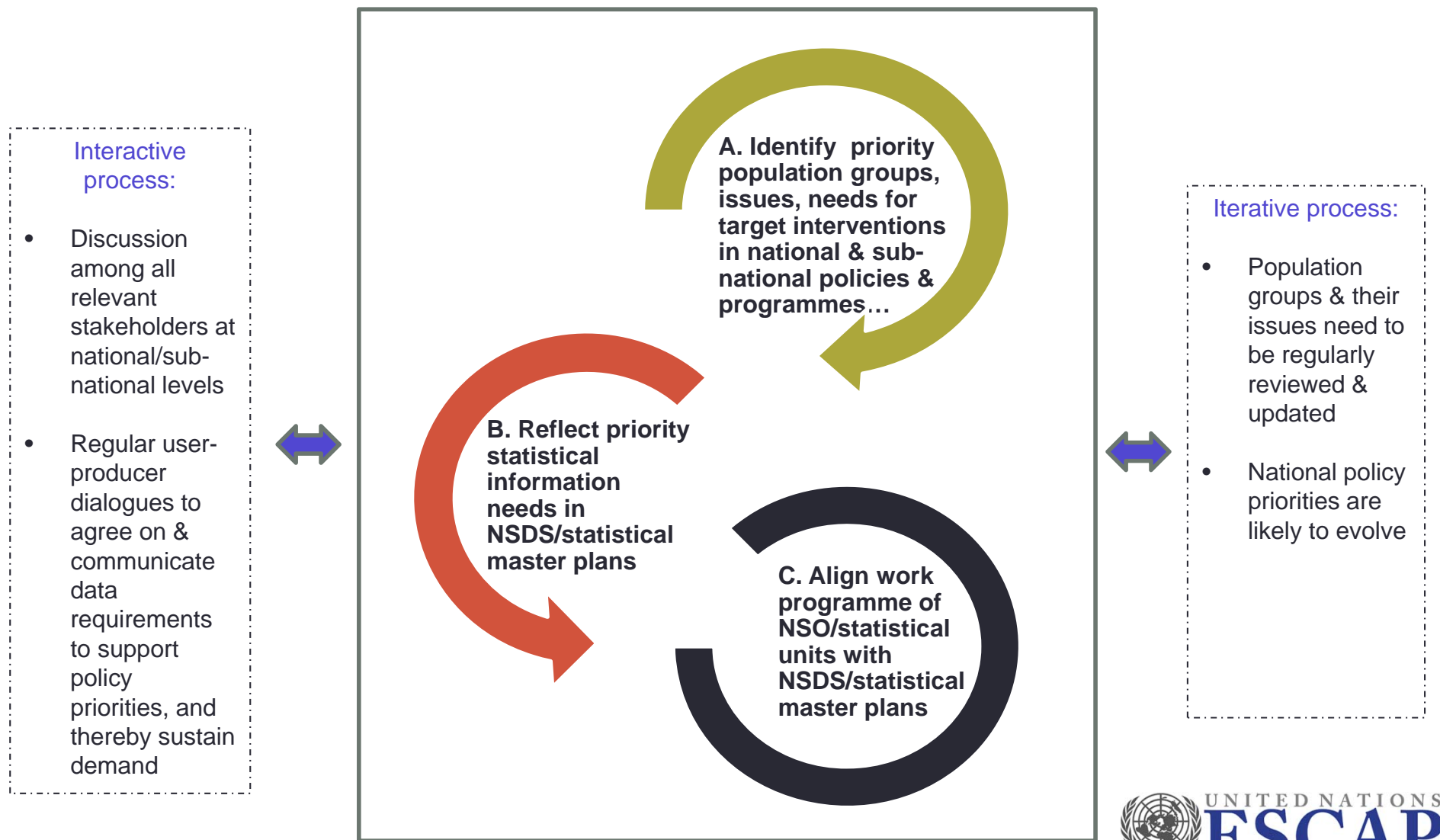
- I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for disability data
- II. Strengthening national data production
- III. Enhancing accessibility, analysis and use of existing disability data at the national level

## Translating disability-related information needs and related challenges into a concrete plan of action to improve disability statistics at the national level...



**What does this mean in  
terms of guidelines for  
national actions?**

# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (1)



# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (2)

Five possible criteria to identify target population subgroups\* that are likely to be left behind

## 1 Hard to reach

Sub-groups of population that are difficult to target for a variety of reasons such as being small (in the minority) or having specific characteristics such as illness, occupation, etc.

## 2 Hidden population

When public acknowledgement of the population is potentially threatening for the members of the sub-group. Size of these population groups is often unknown and strict privacy issues are a concern in identifying them.

## 3 Excluded, marginalized, discriminated

Though the three groups are different, all share the same characteristic, they are often "known" but "ignored" in one way or another. Examples: certain ethnic groups, certain age groups, sex, occupation, religious minority groups.

## 4 Vulnerable sub-population groups

A sub-group that is potentially in a disadvantaged position due to its socio-economic situation. Examples: uninsured, low income, slum, or elderly groups

## 5 Geographically disadvantaged

Sub-populations that live in an unfortunate situation due to geographical conditions such as harsh climate, remote and hard to access locations, poor infrastructure.

Source: UNESCAP: Sustainable Development Goals Baseline Report (2017 expected)

\* Groups are not mutually exclusive and a person may fit more than one group

# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (3)

**A. Identify priority population groups, issues, needs for target interventions in national & sub-national policies & programmes...**

**B. Reflect priority statistical information needs in NSDS/statistical master plans**

**C. Align work programme of NSO/statistical units with NSDS/statistical master plans**

Provide tools/ guidelines for...

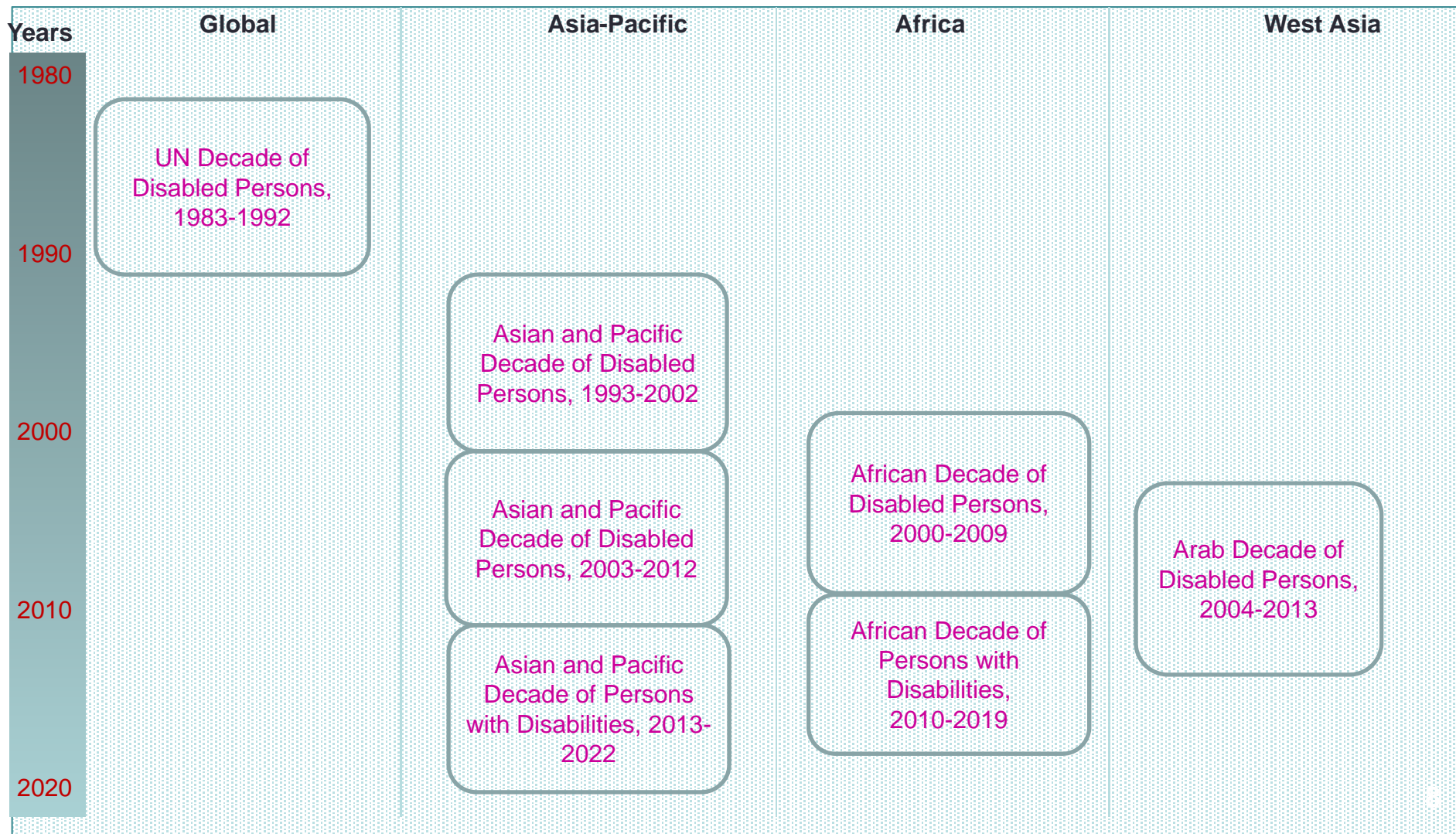
- Review of overall/sectoral plans/strategies for disability-inclusiveness.
- Review/development of relevant national monitoring frameworks to ensure specification of vulnerable population groups & issues:
  - *Information and accountability tools; Political support & investment needed.*
- Guided by/aligned with national, regional & global development priorities as identified in the SDGs, CRPD, Incheon Strategy (A-P region) etc.
- User engagement: NSO/NSS with national/ sub-national policy bodies, & other relevant user groups including the disability community.

- Review/establish statistical mandates and processes to sustain production & dissemination of disaggregated statistics on PWDs :
  - Development/review of the NSDS.
  - *Ensure planning for long term investments needed for production and dissemination of relevant statistics*

- Align with existing government planning cycles.
- Resource mobilization: appropriation of budget/allocation of other resources required.
- Clear identification of roles/responsibilities within and between NSS, policy bodies and other relevant agencies.

# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (4)

## Asia-Pacific disability-related mandates and commitments





# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (5)

Incheon Strategy in Asia-Pac: first set of regionally agreed disability-inclusive development goals

- Rooted in the principles enshrined in the CRPD
- Data collected for the Incheon Strategy indicators could help member States to monitor, evaluate and report on their implementation of the CRPD



1. Poverty reduction & employment
2. Political participation
3. Accessibility
4. Social protection
5. Education
6. Gender equality
7. Disaster risk reduction
- 8. Data collection**
9. CRPD ratification
10. International cooperation

Mix of statistical indicators and indicators on norms

# I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (6)



- Incheon Strategy underpins many of the themes & indicators related to disability of the global monitoring framework for the SDGs.
- Opportunity to rethink the strategic planning process and integrate the “leave no one behind” focus in national policy frameworks

## I. Establishing a well-coordinated policy environment at the national level to ensure effective demand for data (7)

- Guidance to reflect on and identify the roles and responsibilities of key stakeholders
  - Is there a national agency responsible for overall coordination of a disability policy framework/strategy formulation/ implementation/ mainstreaming/ progress monitoring and reporting?
  - What is the role of the national statistical office in the process of policy discussion and developing related monitoring/indicator frameworks?
  - Which agency can/should take lead in initiating discussions on the development of a national action plan for disability statistics?
  - How can the International statistical community/ dev partners assist – type of regional/global support needed?
    - Development of new measurement standards & guidelines
    - Enhancement of skills to apply standards
    - Review of institutional set-up, mandates etc.

## II. Strengthening national data production (1)

- **Should follow policy review process** and development of national monitoring/indicator frameworks for overall/sectoral development plans/strategies
- **Guidance on mapping existing data:** what data exists & where? potential sources?

<b>Population and housing census</b>	<ul style="list-style-type: none"> <li>• Idea of prevalence</li> </ul>	<ul style="list-style-type: none"> <li>• Data can be tabulated for small/local areas</li> <li>• But limited scope of questions; infrequent</li> </ul>
<b>Household surveys</b> Dedicated survey ; Module in surveys on national health, labor force, living conditions, socio-economic etc.	<ul style="list-style-type: none"> <li>• Prevalence rates</li> <li>• Causes / types of disability, underlying health conditions, severity and duration of disability</li> <li>• Use of/ need for assistive devices</li> <li>• Changes in environment</li> <li>• Policies /public awareness on disability</li> </ul>	<ul style="list-style-type: none"> <li>• Flexibility in depth/range of topics; special probes; increased possibility to locate persons with disability</li> <li>• Limited sample size; limited possibility to analyze prevalence for smaller geographical/ local areas; limited coverage of persons living in institutions; limited possibilities for time-series analysis of ad-hoc surveys; need for specialized training.</li> </ul>
<b>Admin sources:</b> Population registers, vital registration systems, social security systems, program records	<ul style="list-style-type: none"> <li>• Trend data on prevalence of impairments or disabilities</li> <li>• Numbers &amp; characteristics of service users , type, quantity &amp; cost of services provided</li> </ul>	<ul style="list-style-type: none"> <li>• Possibility for on-going/regular/annual data; few additional resource needs; possibility for tabulating for smaller geographical areas; short and long-term series; provides sampling frame for in-depth research</li> <li>• Reporting based on when disability was diagnosed rather than onset; inflexible / inefficient registration systems ; double-counting;</li> </ul>
<b>Non-conventional data sources</b>	<ul style="list-style-type: none"> <li>• Big data: e.g beneficiaries who use/do not use benefits etc.; quality / impact of services</li> <li>• Geo-spatial info: e.g. actual / potential beneficiaries.</li> </ul>	<ul style="list-style-type: none"> <li>• Unstructured</li> <li>• Cannot measure e.g. intra-household dynamics</li> <li>• Emerging – more guidance needed</li> </ul>

- Are definitions & concepts used by various agencies consistent in the country – e.g. Is ICF being used as a conceptual framework to improve clarity & precision in the definition/ measurement of disability in the country?

- Are intl. measurement standards/ guidelines being followed?

## II. Strengthening national data production (2)

### ➤ Guidance on assessing quality of existing data

#### A framework for considering the quality of statistics

##### Relevance

The degree to which statistical information meets user needs

- Concepts, definitions and classifications correspond to user needs
- Data are disaggregated to levels needed for policy design and monitoring

##### Accuracy

Statistics accurately and reliably portray reality

- Information on the extent of sampling and non-sampling errors is available
- Mechanisms exist for providing feedback      ■ Handling errors and revision

##### Timeliness and punctuality

How fast after the reference date data are released; data delivered when promised

- Time taken before release is reasonable and within any agreed timeframes
- Release calendar outline expected publication dates

##### Accessibility and clarity

Can be found/obtained without difficulty, is presented clearly and can be understood

- Available and accessible on an impartial basis      ■ Data are clearly explained
- Various convenient formats      ■ Free of charge or affordable

##### Comparability

Data are internally consistent and comparable over time

- Based on common standards
- Any breaks in series are explained (e.g. due to changes in methods or definitions)

##### Coherence

Possible to combine with related data from different sources

- Concepts, definitions and methods are aligned across different collections
- Differences between related sources are explained

Source: Adaptation of the United Nations Generic National Quality Assurance Framework

## II. Strengthening national data production (3)

### ➤ Guidance on disaggregated data

#### ❖ SDG indicator framework:

- ❖ Standardized disaggregation at global level for international comparability (e.g. age , sex) embedded into indicator.
- ❖ By population characteristics that may vary across countries depending on policy priorities – income, sex, age, race, ethnicity, migratory status, **disability**, geographic location, or other characteristics...

#### ❖ **Disaggregating outcomes** by disability status (education, employment, etc.)

#### ❖ Significant **variations may be seen by adding multiple characteristics** simultaneously:

- E.g. PWD by sex by age by location and more...
- Identify vulnerable population subgroups falling farthest behind

#### ❖ Surveys data:

- May be relatively easy to disaggregate with inclusion of appropriate questions
- However, typically designed to produce national averages; mask disparities; inadequate sample size to cover population groups of interest at sub-national levels; limited frequency; time lag in data processing.

## II. Strengthening national data production (4)

### ➤ Opportunities for production of relevant disaggregated data

#### Harnessing Big data

- Data produced by social media, mobile phones, scanners, image analysis etc.
- Can provide data about population groups that are likely to be excluded from traditional data sources and generate information on various aspects of life not captured by conventional data collection.
- Needs to be harnessed efficiently and in accordance with quality assurance frameworks.
- Challenging: data unstructured and not necessarily produced for statistical purposes.

#### Increasing micro-data access

- To users, including academia and civil society.
- In-depth analysis of micro-data for understanding of who is left behind and what interventions are effective.
- Factors: National context, legislation, public attitudes etc.
- Protect confidentiality; Consistent with legal requirements; Transparent procedures; Used exclusively for statistical purposes.

#### Joining up existing data from different sources – data integration & using advanced statistical methods

- Combining data from pop registers, pop & housing censuses, sample surveys.
- Estimates of acceptable precision for smaller geographical areas or sub-population groups (small area estimation techniques).
- Efficiency & cost-effectiveness.
- Issues: legal/institutional issues related to data sharing; technical expertise; adequate sample size for reliable estimates? how to protect confidentiality?

Source:

(1) UNESCAP: Sustainable Development Goals Baseline Report (2017 expected )

(2) Managing Statistical Confidentiality and Microdata Access (UNECE, 2007) & United Nations Fundamental Principles of Official Statistics

## II. Strengthening national data production (5)

### ➤ **Guidance on expanding data collection/production**

#### ❖ **Integrate** information needs on disability in existing surveys/censuses:

- Allows for disaggregation of existing indicators that are well-understood
- PWD issues as core policy issues
- Cost effective

#### ❖ Conduct **dedicated disability surveys** or add **modules on disability issues** in other relevant sample surveys using common/consistent approach:

- Obtain info beyond what existing instruments are designed for
- Need different sample to disaggregate results by e.g. type of disability / other sub-population characteristics
- Use of harmonized concepts & definitions in the country
- Selection of appropriate/relevant intl. measurement standards/ guidelines

#### ❖ Improve **administrative sources** by working with relevant Ministries: health, education, labour etc.



## II. Strengthening national data production (6)

### ➤ **Guidance on expanding data collection/production**

- ❖ Adopt agreed quality standards, procedures and good practices including:
  - Consistent approach – meet needs of users within each line ministry as well as cross-cutting issues
  - Coordinated data collection across NSS – definitions, measurement standards etc.
  - Selected & focused areas e.g. labour statistics on PWDs; gender-responsive disability statistics for enhanced relevance & quality

## III. Enhancing accessibility, analysis and use of existing data at the national level (1)

- Data accessibility to wide user community, including govt agencies, civil society, academia, business sector:
  - Regular publication of key relevant indicators at national/local levels
  - Standardized metadata for principal data sources to allow for comparison
  - Common repository for disability data
  - Use of web-based platforms, data dissemination/visualization tools
- Good practices on thematic analysis and interpretation of indicator data/ micro-data -> understand drivers of disability policy issues/evidence-base for policy formulation
- Statistical literacy - understand/interpret statistical information/multi-dimensional concept of disability
- National user-producer dialogues/ partnerships

Addressing data gaps and challenges: need for action across entire range of building blocks of NSS depending on individual country strengths, challenges, priorities etc....

<i>Institutional capacity component</i>	<i>Desired State</i>
1. Legal framework	Existence and implementation of a modern statistical law that applies the FPOS
2. Strategic planning	Strategic planning is not solely output-based but incorporates policies and resource requirements and is linked with national development plans
3. Advocacy for the improvement of national statistical systems	Advocacy is intended to galvanize political and financial support to implement a national statistical plan comprising all statistical domains and all producers of official statistics
4. Coordination among agencies of the NSS	Coordination among national agencies involved in the production and dissemination of official statistics is assured through the development and implementation of national plans as well as regional coordination in provision of tools and support
5. Engagement between data users and data producers	Mechanisms to engage users and producers, such as user-producer dialogues are in place
6. Modernization of statistical organizations	Organizations of the NSS use international tools and standards for mapping and rationalizing business processes and building modern IT and metadata infrastructures
7. Quality assurance and dissemination policies	Quality assurance and dissemination policies are put in place
8. Human resources and skills	Subject-matter expertise and technical skills, human resources policies, managerial/leadership, and communication related skills
9. Statistical infrastructure	Statistical infrastructure, including methods and practices, IT, metadata repositories
10. Data sources	Ability to draw on many data sources, from statistical collections, administrative registers and new (non-traditional) sources; data sources are chosen based on quality including timeliness, and cost

# The 2001 principles and guidelines on disability statistics

Interspersed across....

## Planning and organization of collection of data on disability

- Preparatory activities:
  - Objectives of the study; consulting users/PWD; examining existing data; defining the population with disabilities; publicity to promote data collection effort
- Design of questions to identify PWD:
  - Definitions; wording of questions; cultural relevance of questions; appropriate instrument
- Data collection design and operations:
  - Choice of respondent; mode of data collection; translation of questionnaires; data processing; planning data dissemination

## Methodology for disability data collection

- Censuses
- Surveys
- Sampling for disability survey
- Data on disability in institutions

## Dissemination and use of disability data

- Planned tabulations
- Reports & publications
- Other forms of dissemination and use
  - Unpublished data/Micro-data; special tabulations; on-line dissemination & computer access to data
- Indicators
  - That measure presence of disability; equalization of opportunities; disability-free life expectancy

# Issues for consideration

- Structure the guidelines along the 3 broad elements:
  - Establishing a well-coordinated policy environment at the national level to ensure effective demand for disability data
  - Strengthening national data production
  - Enhancing accessibility, analysis and use of existing disability data at the national level
- Central focus: “leave-no-one-behind”:
  - More comprehensive discussion on identification of priority population groups and issues as well as importance of disaggregated data and methods/opportunities
- Beyond statistics!
  - Development/ review of overall/sectoral/disability-specific national plans and strategies for inclusiveness and to ensure specification of priority population groups and issues
- National monitoring and indicator frameworks:
  - Target setting, identification of relevant indicators, related data sources & measurement frameworks
  - As information and accountability tools to obtain political support and investment needed
- Target users of the guidelines:
  - All relevant agencies (beyond national statistical offices/system) to encourage a consistent approach to data production and utilization at national level OR
  - Only target national statistical offices/systems and highlight their role and responsibilities in such a process and at which steps they can take lead?

# Issues for consideration

## TRAINING MANUAL on DISABILITY STATISTICS



World Health Organization /  
United Nations Economic and Social Commission for  
Asia and the Pacific

2008



### Drawing on existing resources – possibility to integrate?

- Intended to enhance understanding of the ICF-based approach to disability measurement.
- Overview of ICF framework, guidelines on how to operationalize the underlying concepts of functioning and disability into data collection, dissemination and analysis.
- More specifically: covers ICF approach and its application; data collection methods and instruments; planning and measurement issues; instrument development/testing/fieldwork; data processing/analysis/dissemination; as well as use for policy formulation

## Statistics@ESCAP

<http://www.unescap.org/our-work/statistics>

<http://www.unescap.org/committee/committee-on-statistics>

[http://data.unescap.org/escap\\_stat/](http://data.unescap.org/escap_stat/)

## Disability and the Incheon Strategy

<http://www.unescap.org/our-work/social-development/disability/about>

<http://www.maketherightreal.net/incheon-strategy>

<http://www.maketherightreal.net/midpoint-review>