Are persons with disabilities included in the effort to leave no-one behind?

Mapping disability data in development in Asia and the Pacific

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ASEAN Disability Forum

Pacific Disability Forum

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inclusion advisory group

UNFPA

Asia and the Pacific

As the United Nation's sexual and reproductive health agency, UNFPA's mandate is grounded in the Programme of Action of the 1994 International Conference on Population and Development, which calls for the realization of the rights of all persons. This includes people living with disabilities and their participation in all aspects of social, economic and cultural life.

In the Asia Pacific region, UNFPA and partners work together to implement the Incheon Strategy to "Make the Right Real" for Persons with Disabilities. The Incheon Strategy is the region's first set of disability-specific development goals to track progress towards the fulfilment of rights of persons with disabilities.

In the region, it is estimated that there are over 650 million persons with disabilities. However, without accurate, timely and disaggregated data, countries are unable to develop effective policies and programmes, monitor the wellbeing of persons with disabilities and evaluate the equity and impact of development efforts. This endangers country commitments to 'leave no one behind' and undermines their obligations to the Convention on the Rights of Persons with Disabilities.

This groundbreaking report demonstrates the importance of ensuring data is inclusive and provides recommendations for immediate action in order to improve the collection, analysis and reporting of disability data. We hope this report will be used as a tool for future advocacy and ultimately better data for all.

Björn Andersson
Regional Director
UNFPA Asia and the Pacific

> **“We have to understand what data on persons with disabilities is being collected, why it is collected and how it is being used. With this evidence, we can influence advocacy and investments for true inclusion of persons with disabilities. It is only with data on the experiences of persons with disabilities that we can truly understand who is being left behind in development processes and how we can effectively address this.”**

José Viera
Permanent Representative
Stakeholder Group of Persons with Disabilities

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“We commit to building a world that is accessible to everyone. Making that a reality requires removing the persistent barriers that still exclude far too many. It demands going beyond assumptions about what a disability “looks” like. It means meaningful participation of persons with disabilities and living up to the call for, “nothing about us, without us”.

How can we ensure everyone realises their rights and choices? What must happen to make services accessible and to open equal opportunities to live and thrive? How do we rid societies of the stigma and discrimination that persons with disabilities all too often face? As we seek to achieve the Sustainable Development Goals by 2030, these are questions that we must answer – and act on – urgently.”[1]

Natalia Kanem
Executive Director
UNFPA

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[1] https://www.unfpa.org/press/health-systems-we-build-back-after-covid-19-must-reach-everyone

Summary

- Data is essential for government officials and policy makers to fulfil the rights of persons with disabilities. Understanding what, why and how data is collected is important to inform future advocacy and investment in disability data.

- In 2021, a mapping of the status of national collection from censuses and large household surveys including the use of disability data in the Asia and Pacific region was undertaken through the United Nations Population Fund (UNFPA) Asia Pacific Country Offices. A sample of persons with disabilities also shared their experiences around disability data.

- Most of the respondent countries have significant gaps in their overall technical capacity to produce critical development indicators on disability regardless of the population group.

- Although many respondent countries can disaggregate the indicators they produce, very few are using questions framed around functioning to identify persons with disabilities, for example, the Washington Group questions. This raises questions on the quality, usefulness and comparability of the data.

- Capacity varies greatly across the region; with half of the respondent countries unable to produce and disaggregate by disability in two of the six indicators examined more closely in the survey.

- Only 1 in 4 countries sampled in the Asia-Pacific region could monitor critical disability inclusion indicators relating to healthcare access.
- Only 1 in 5 countries sampled in the Asia-Pacific region were using internationally recommended methods for identifying persons with disabilities in their national data systems.
- Only in 1 in 4 countries sampled in the Asia-Pacific region were systematically identifying and reporting on barriers and enablers for persons with disabilities to access education.
- Many persons with disabilities are concerned about inadequate data and evidence around disability, but do not feel they know enough to confidently use or advocate for better data.

High-level summary of recommendations

National Statistical Offices (NSOs)

- Incorporate the Washington Group Questions into upcoming national censuses and surveys, prioritising key data gaps such as health.
- Articulate technical assistance needs including capacity development to aid advocacy and investment decisions.
- Plan analysis of key development indicators where disability data has been collected but not yet used for disaggregation.

Donors and technical partners

- Provide support for:
    - Dedicated technical assistance and capacity development packages to NSOs that report a lack of capacity, including supporting peer learning and exchange.
    - Further research into the reasons for current data gaps.
    - Research into clear recommendations for data that can be used to drive efforts for reducing disparities in areas such as the barriers and enablers to employment and education.
    - Disability-specific surveys to provide more detailed insights not currently captured in existing indicators.

Organisations of Persons with Disabilities (OPDs) and their civil society partners

- Articulate the key priorities of the national disability movement and related data needs – such as employment, primary education and health – in order to help governments, and prioritise data collection and analysis efforts.
- Create awareness within various levels of governments of disability data needs and good practice.
- Develop the capacity of OPD members and allies to understand, appropriately use and advocate for improved disability data, through multi-stakeholder training, data processes and other means.

Multi-stakeholder

- Establish a regional, cross-stakeholder working group of disability data advocates to develop a resource mobilisation and investment advocacy work plan for disability data.
- Bring together statisticians, policymakers, United Nations (UN) agencies, OPDs, and Non-Governmental Organisations (NGOs), to exchange information, learn from one another and create evidence-based policies for sustainable change.

Introduction

The purpose of this report is to inform advocacy and investment efforts to improve the collection, analysis and use of disability data, and through this, more effective, accountable and inclusive policy, programming and investments. It is based primarily on a mapping done through the UNFPA Country Offices in Asia and Pacific region of the capacities of countries to produce key population-based indicators disaggregated by disability. It is not a comprehensive or definitive view of what is happening across the 36 countries in the region. Rather, it reflects the overall trends and findings from 20 respondent countries.

The survey builds on other initiatives, including the UN SDG Data Platform, the Disability Data Initiative and the ESCAP Midpoint Review of the Asian Decade of Disability. It is complemented by targeted interviews with persons with disabilities on their related experiences.
The report is set against a policy background recognising that **data is essential to fulfilling the rights of persons with disabilities – who are all too frequently left behind in development processes and outcomes.** The main drivers of policy on disability and data stem from international and regional norms and agreements; recognising the importance of data collection in putting the rights of persons with disabilities at the heart of countries' development efforts and for monitoring progress towards development goals. These include:

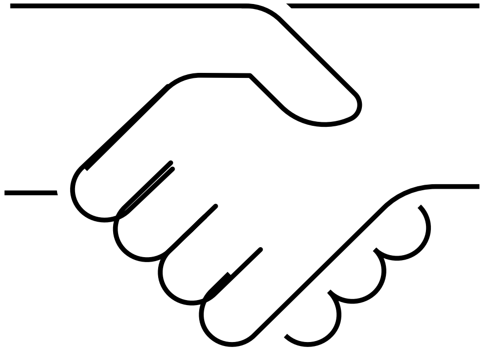
- **The Convention on the Rights of Persons with Disabilities (CRPD).** Its purpose is to promote and protect the full inclusion of persons with disabilities into society and to ensure the full enjoyment of their human rights. Article 31 of the CRPD explicitly calls for the collection of data to enable the formulation and implementation of policies.

- The Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific (2013-2022). The strategy includes an extensive set of targets and indicators for monitoring its implementation and impact. As this strategy reaches its end point, it will be critical to understand what countries are able to report in order to track progress and inform next steps in advocacy and investment.

- **The 2030 Agenda for Sustainable Development** and linked global indicator framework measuring progress of the Sustainable Development Goals.

These instruments recognise the importance of data collection, analysis and application as a means to enable government and other stakeholders to identify, understand and overcome the disparities faced by many persons with disabilities in important areas such as income, employment, education, living conditions and health. It can also identify human rights violations such as abuse and violence, which disproportionately affect persons with disabilities. The absence of accurate, timely and disaggregated data on disability means governments are unable to track progress or identify gaps in the wellbeing of persons with disabilities or evaluate the impact of development efforts.

> **"When project designs are happening around development, if there is no consideration for people living with disabilities, you are often getting a generic design document and design process that has no considerations for those in our community who may be the most vulnerable."**
>
> Litea Biukoto
> Team Leader - Disaster Risk
> Pacific Community



This report resulted from a partnership between UNFPA Asia-Pacific and CBM Global Disability Inclusion, in close collaboration with the Stakeholder Group of Persons with Disabilities, the International Disability Alliance, as well as national and regional OPDs, including the ASEAN Disability Forum and Pacific Disability Forum. The partnership aims to build resources, awareness and capacity around disability data with key stakeholders, including OPDs, national statistics offices, donors, related UN entities and others, drawing from experiences and resources in the Asia Pacific region. The project resources and lessons will act as a foundation for expanding disability data literacy training and future advocacy in the region and more broadly.

Methodology

A survey was piloted and then sent to each UNFPA country office representing the 36 countries in the UNFPA Asia and Pacific region.

The UNFPA county offices were requested to gather information from relevant sources such as NSOs and other government focal points responsible for monitoring the Incheon Strategy indicators and corresponding Sustainable Development Goals (SDGs) indicators. It was apparent from the survey that the level of knowledge and ease of collecting this data varied widely across respondents.

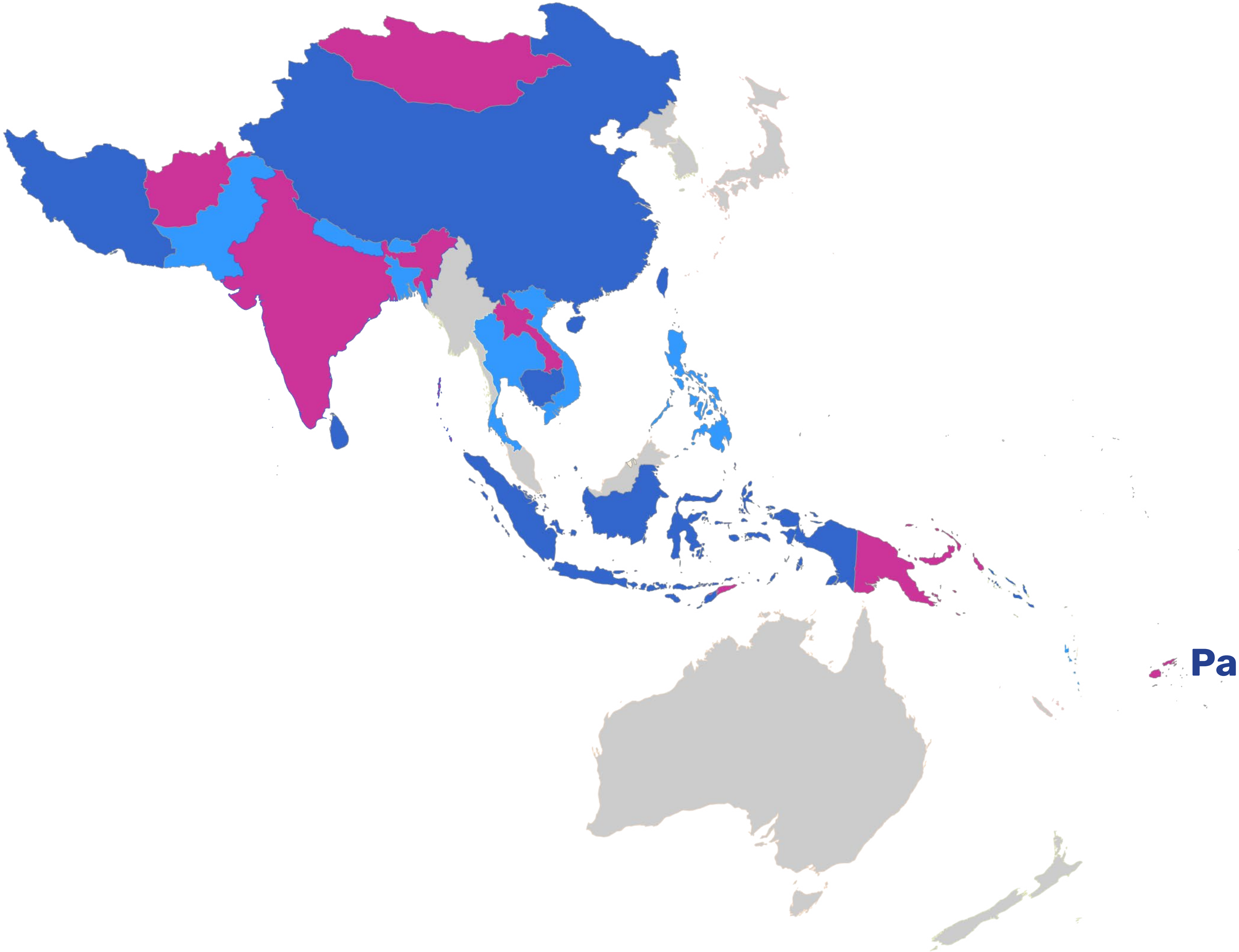
The survey had three parts:

- The first part focused on a specific set of common national data systems operated by the NSO and other ministries, such as population censuses and various household surveys and the Incheon Strategy indicators that are collected in each.
- The second part focused on a set of six key Incheon Strategy indicators that tracked development outcomes for persons with disabilities relating to poverty, employment, education, and health care.
- The third part focused on the availability of other disability data, for example, through the publication of a national disability report or other data sources.

Twenty of the 36 countries responded to the survey and provided information to inform the following overarching questions:

- Which indicators can they produce and disaggregate (or plan to in the future)?
- What questions do they use to determine disability status?
- What challenges do they face in collecting and disaggregating data?
- What efforts are they taking to collect data on barriers and enablers for persons with disabilities to access education and employment?

Countries that responded to the survey



Afghanistan
Bangladesh
Bhutan
Cambodia
China
Fiji
India
Indonesia
Iran
Kiribati
Lao PDR
Mongolia
Nepal
Pakistan
Papua New Guinea
Philippines
Sri Lanka
Thailand
Timor-Leste
Vietnam

Respondents reported gathering information from a number of sources, including national statistics offices representatives, government disability focal points, UNFPA country office staff and national OPDs. Given that no individual respondent had complete knowledge of all the data collected in their country it was necessary to cross-reference responses with published reports and external sources, such as the Disability Data Initiative, in order to resolve any inconsistencies.

The mapping represented 55 per cent of possible countries surveyed through the UNFPA country offices. The limited sample size and representativeness of the sample is unclear, as reasons for not responding are unknown. The virtual survey was conducted during the COVID-19 pandemic with many countries in lockdown and experiencing a high number of COVID-19 cases, which may have impacted the response rate. This may lead to under-reporting of disability data activity. For example, the ability to disaggregate census data by disability is wider than is reported here, as a number of non-responding countries, especially in the Pacific region, have had dedicated donor and technical support to include disability indicators in national censuses and related analysis and public reports. Despite these limitations, useful trends are apparent across the data suggesting recommendations for further comprehensive research and investment around disability data.

The mapping was complemented by targeted interviews with persons with disabilities and their allies involved in disability and data efforts. This helped to verify, explore and extend the emerging themes. A short survey was distributed by OPDs to their members and interviews were held with a targeted sample of individuals known to be involved in disability data and advocacy in the region. Individuals were invited to share stories and reflections on disability data processes and outcomes, and about related advocacy efforts and data needs.

Findings

Which indicators can be produced and disaggregated, and what challenges are faced?

The first part of the survey attempted to obtain an overall indication of the country's ability to produce the full set of population-based Incheon Strategy and SDG indicators from each of a core set of data collection platforms. Questions were asked about censuses, Labour Force surveys, Household Income and Expenditure surveys, Multiple Indicator Cluster Surveys (MICS), Demographic and Health surveys, Health surveys, Education surveys and Disability surveys.

Incheon Strategy/SDG indicators

- Only 9 of the 20 respondent countries were able to produce and report on more than a third of the Incheon Strategy indicators from their most recent census or surveys and none of countries were able to produce and report on all of the Incheon Strategy indicators (or SDG equivalents) from either their most recent or upcoming census or surveys. Incheon Strategy and SDG indicators were more likely to be produced from censuses rather than surveys, which is a disadvantage given the 10-year period between censuses.

- 16 out of 20 respondent countries have collected information on disability or plan to do so in their next census. Bhutan, Cambodia, Fiji, India, Indonesia, Kiribati, Lao PDR, Mongolia, Nepal, Philippines, Sri Lanka, Thailand and Timor-Leste collected information on disability in their most recent census. Bangladesh, Pakistan and Papua New Guinea reported that they will include information on disability in their upcoming census. Viet Nam conducted a national survey on persons with disabilities in 2016. Iran included questions on disability in the 2011 census but not in the 2016 census.

In China, the second and the most recent national survey on the population of persons with disabilities was conducted in 2006. The implementation of a census or other household surveys in Afghanistan is unknown at the time of publication of this report.

- 8 out of 9 countries that reported on employment data indicated that they could produce employment data disaggregated by those with and without disabilities. This was closely followed by indicators related to primary education, with 8 countries that collected data on primary education and were able to disaggregate by disability status.

Most of the time, when the indicators can be produced in a census they can also be disaggregated to separately identify the population of persons with disabilities and without disabilities and compare how those with disabilities and those without are faring on the indicator. However, the findings from this study suggest that **while some countries collect data that would allow them to disaggregate certain indicators by disability, they are not analysing the data.** Further research is needed to understand and then address this.

In addition, most persons with disabilities interviewed had only engaged with formal data around census advocacy – often with decade-long gaps in collection – resulting in limited opportunities for influence. Except for previous work in the Pacific region, **there was limited knowledge amongst members of the disability movement interviewed in Asia of other data surveys and how they could be used.**

Multiple Indicator Cluster Surveys (MICS) and Household surveys

The inclusion of disability questions was less common in household surveys compared to censuses (13 out of 20). Aside from targeted disability surveys, MICS were the most likely to include disability questions, as seen in Table 2. Only 5 of the 13 countries reported that their Labour Force surveys included questions to identify the population with disabilities. Given employment-related indicators were the most likely to be able to be produced, this is a lost opportunity in an area that is a high priority for many persons with disabilities.

The second part of the mapping survey focused on disability disaggregation across six key Incheon Strategy indicators relating to poverty (1.1), employment (1.2), healthcare (4.1), early childhood intervention (5.1), primary education (5.2) and sexual and reproductive health services (6.3).

One country reported they could produce all six indicators but would need technical assistance to do so. This highlights the need for further technical assistance, especially in instances where data is already collected and available for analysis and reporting. Three countries reported they could produce five of the six indicators. Seven countries could produce none or one indicator. This highlights that data capacity varies greatly across the region; with half of surveyed countries unable to produce more than two of the indicators and some countries reporting an ability to produce an indicator but not demonstrating that in practice through publicly available data. Other countries stated that they would require a national disability survey in order to produce these indicators, when in fact five of the six indicators could be produced by adding disability identification questions to a general population census or survey; a comparatively low-cost alternative.

However, increased investment, training and quality assurance is required to implement this solution. Collecting information on disability is sensitive; it requires specific protocols and skilled enumerators to ensure that the information collected is consistently of high quality. This is particularly true for censuses. Indicator 5.1 may require more information that is better gathered in a disability survey because it is an indicator of childhood interventions related to disability.

The indicator that most countries could produce was 1.2 (ratio of persons with disabilities in employment); although some countries determined disability status through a disability certification system rather than through questions about functional difficulties. Only five countries reported being able to produce the disaggregated indicator on the proportion of people living below 50 per cent of median income, by sex, age and disability status, and five countries (Cambodia, India, Pakistan, Fiji and Kiribati) were able to report on the Incheon 6.3 indicator and disaggregate by disability using their most recent data systems.

> **“In the health system, there is not enough data on how many women with disabilities are getting pregnant every year, How many women with disabilities are unable to access contraception and sexual reproductive health information or how many women with disabilities may be dying during childbirth every year because of their disability? This kind of data is not available and because of that, it is challenging to convince the decision makers and other stakeholders to say that the needs of women with disabilities need to be addressed.”**
>
> Priskila Arulpragasam
> UNFPA Sri Lanka

Table 1: Known presence of disability questions in censuses and household surveys

Survey	Number of countries reporting	Number with disability questions
Censuses	20	13
Labour Force survey	13	5
Household Income and Expenditure survey	14	7
Demographic and Health survey	9	4
Multiple Indicator Cluster Surveys (MICS)	10	8
Health survey	6	3
Education survey	2	0
Disability survey	5	5

Notably, **health sector indicators were reported by the fewest number of countries. As a result, overall information on these indicators – and for the population of persons with disabilities – is unavailable in numerous countries in the region for planning or service provision.** This is concerning for several reasons, highlighted by the World Health Organisation. First, persons with disabilities are often generally disadvantaged in health services, being three times more likely to be denied health care and 50 per cent more likely to suffer catastrophic health expenditure. Second, in the context of the global COVID-19 health emergency, persons with disabilities are disproportionately affected.

Overall, many countries are not producing or face challenges in producing official data disaggregated by disability. To address this gap, persons with disabilities generally described their OPDs as taking two broad steps. The first was seeking to influence their governments for improved disability data. This requires OPDs to have a good understanding of how to analyse what data is available and what to recommend as good practice in data collection, analysis and reporting; something many felt underprepared to do.

The second related to producing and using citizen-generated data, including surveys of their members and assisting other organisations – such as non-government development organisations – in their programme data collection. Others used case studies or personal stories to highlight the complex, intersectional and often multi-discriminatory nature of the disability experience, such as indigenous women with a disability living in remote areas; something that lends weight to further data disaggregation.

“The impact of inadequate data gathering or even a detailed database of persons with disabilities has been felt during the pandemic. Because the database is not updated, it affects how you are able to access support services.”

Attorney Krissi Shaffina Twyla Rubin
Philippines’ Gender Equality
& Women’s Human Rights Center

Countries’ ability to produce and disaggregate by disability was explored on six Incheon Strategy indicators:

1.1 Proportion of persons with disabilities living below the US$1.25 (PPP) per day, the international poverty line, as updated by the World Bank and compared to the overall population.

1.2 Ratio of persons with disabilities in employment, as compared to the general population.

4.1 Proportion of persons with disabilities who use government-supported healthcare programmes, as compared to the general population.

5.1 Number of children with disabilities receiving early childhood intervention.

5.2 Primary education enrolment rate of children with disabilities.

6.3 Proportion of girls and women with disabilities who access the sexual and reproductive health services of government and civil society, compared to girls and women without disabilities.

Citizen-generated data is data individuals, communities or their organisations produce to directly monitor, demand or drive change on issues that affect them.

What questions do they use to determine disability status?

The questions used to determine disability status varied widely. For example, many countries asked questions about “disability” rather than questions related to functioning. India, Iran, Nepal and Timor-Leste asked about “disability” rather than difficulties doing daily activities, but then collected some information about the type of disability or impairment. Nepal collected some additional information on functional limitation. Disability certification systems rather than questions about functional difficulties were often used in employment indicator disaggregation.

> **“We have to develop a pool of resource persons (in the local disability movement), who are really clear on disability data advocacy and who can support others to understand things like the Washington Group Questions and usability. We need this pool of resources to share across the different constituency. First we need a consensus across the local (disability) movement - so we all use the same words with advocacy with NSO and other data related authorities.”**
>
> Khom Raj Sharma
> Nepal OPD representative
> Nepal

Recommended questions for disability data

THE SHORT SET

The Washington Group Short Set on functioning (WG-SS) questions has been used by over 80 countries and is widely recommended for identification of persons with disabilities in surveys and censuses. WG-SS are designed within a functional approach and purposely avoid use of the term ‘disability’.

The WG-SS is also widely endorsed by the disability sector and allies for **SDG data disaggregation** by disability for adults that is internationally comparable and comparable over time. For disaggregation by disability among children the recommended tool is the UNICEF/Washington Group module on Child Functioning. Both instruments can be easily and cost effectively inserted in all national data collection efforts. They are also increasingly used by organisations to identify and disaggregate data in development and humanitarian programming.

1 **Do you have difficulty seeing, even if wearing glasses?**

2 **Do you have difficulty hearing, even if using a hearing aid?**

3 **Do you have difficulty walking or climbing steps?**

4 **Do you have difficulty remembering or concentrating?**

5 **Do you have difficulty (with self-care such as) washing all over or dressing?**

6 **Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?**

a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

A useful way of raising awareness and demonstrating the value and process to other countries would be via peer exchange and documenting lessons learned from those countries that are collecting and disaggregating data on disability.

Five respondent countries (25 per cent of total) were using or planning to use the Washington Group questions to identify persons with disabilities. Thailand and Vietnam both used the Washington Group Extended Set and Child Functioning Modules in their national disability surveys, but not in their general data tools. In Indonesia, the questions took a functional approach that reflected some WG-SS questions, but with slightly altered domains around things like emotional and behavioural difficulty.

Fiji reported that although the Washington Group questions are used in their data instruments, they doubted whether enumerators were administering the questions correctly. This is critical for data quality and likely an issue in countries other than Fiji, highlighting the importance of training and monitoring.

Others were collecting data using the WG-SS questions – such as for prevalence data – but not using them to disaggregate indicators of development progress.

When specified, the reasons listed were primarily around capacity and a need for technical assistance to both collect and analyse the resultant data, or because of a lack of awareness of need or next steps. A useful way of raising awareness and demonstrating the value and process to other countries would be via peer exchange and documenting lessons learned from those countries that are collecting and disaggregating data on disability.

> **“Good practices and examples from other countries are useful and needed. We need to see which countries in the region have done monographs on disability. We need to see what would be a good standard and quality outline to ensure the data is available for programs, planning, policymaking and provision of services.”**

Dr. Kambiz Kabiri
Programme Analyst P&D/Ageing
UNFPA I.R. IranSPC

Data on barriers and enablers for persons with disabilities to access education and employment

The third part of the survey focused on the availability of other aspects of information on disability. Information was requested on the publication of a national disability report or plans to publish one.

- Only seven countries (Bhutan, Cambodia, Indonesia, Kiribati, Philippines, Timor Leste and Vietnam) reported that they produce national disability reports containing information on barriers and enablers to employment.
- Five countries (Cambodia, Indonesia, Kiribati, Nepal and Vietnam) include information on barriers and enablers to education.

This is a significant gap as this information is critical to inform efforts to overcome exclusion in areas that are frequently high priorities for persons with disabilities and their representative organisations.

Many OPDs focus their own disability data efforts on advocacy to address these gaps – such as through questions in MICS – or gathering their own data to supplement the national gaps – for example, through member surveys.

> **“Our agenda is based on the needs and the challenges people with disabilities face. The question we always ask is: how do we work towards disability inclusion within the indigenous people’s movement?”**

Pratima Gurung
National Indigenous Disabled
Women Association Nepal (NIDWAN)

OPD roles in national data processes: reflections from the Pacific Disability Forum (PDF)

The Pacific Disability Forum is the regional body of Organisations of Persons with Disabilities (OPDs) in the Pacific. Their strategy recognises the importance of data and evidence to influence policies and programs across the region. Since 2015, they have worked in disability data in several broad areas.

The first area relates to continuously building the capacity of OPDs to understand and engage with disability data, in particular, the WG-SS. This includes supporting OPDs to understand their role in advocating for design, collection, analysis, interpretation and reporting on data. This forms a foundation for subsequent activities.

The second area relates to advocating for inclusion of the WG-SS in national census and population surveys. As countries across the Pacific have begun to include these questions in their national censuses, they are able to develop a picture of the prevalence, level of severity and disparity through disaggregation on issues that are important to their members, such as education, employment and health. Their next question to address this disparity becomes, “what are the barriers or what will enable participation?”.

The PDF and their members are now advocating for these questions to be included in MICS in the region, starting with Fiji.

The third area involves participating in and aiding in the collection, analysis and interpretation of data. This includes contributing to training NSOs and enumerators at in-country analysis workshops, with NSOs and government agencies jointly responsible for interpreting the disaggregated data. NSOs are guided by the data users on both the need as well as how the report should be developed.

For example, in education, the OPD can ask this question, which can be disaggregated by sex, age group, location, and completion rate. “Is there disparity between children with and without disabilities? If yes, why? Is it due to location or their gender?” This instructs on disaggregation and reporting, making the data more useful for those involved in policy and programming.

Their reflections on lessons include:

Continuous investment in OPD capacity to contribute to the design, collection, analysis, interpretation and reporting of data. Training can be supplemented with their own use of the disability indicators in a project.

This helps them first understand how it works and how they can use it before engaging at a national level of data collection, analysis and interpretation.

The importance of technical and donor investment partners in progress. Things like multi-stakeholder technical support to NSOs and analysis workshops effectively cease without donor support.

The importance of joint analytical processes that strengthen commitment from government stakeholders to disability inclusion.

Having a long-term view: in some settings, it has taken over two years of advocacy efforts to succeed in getting the correct disability indicators in a data set.

Continue advocating for the collection of other information in population surveys like the MICS that is not provided by the WG-SS, such as any barriers to participation and support needed.

Recommendations

Given limitations in the respondent data, it is likely there are more countries than indicated here that can produce the Incheon Strategy/ SDG indicators and can disaggregate them by disability status – particularly in the Pacific, where there has been considerable donor investment in this space. The recommendations below are based on the responses received. While the situation is likely more favourable than indicated in the mapping, it is likely that major data gaps still exist. The recommendations are designed to fill that gap.

Support data collection activities for development reporting and

Tracking progress by using disability disaggregated data is a critical step to measuring success and identifying any differences between the population of persons with disabilities and those without disabilities. In addition, information is needed on barriers and facilitators to understand how to address this gap. The difficulties many countries had with reporting on SDG or Incheon Strategy indicators could be viewed as an opportunity to ensure that any efforts to support them can involve disability considerations from the outset.

1. Raise awareness of Incheon Strategy and SDG reporting needs and clearly map linkages between them; noting those that are the same and those that, while different, address similar issues in different ways. This simple, practical resource could aid reporting and priority setting.

2. Invest to expand collection of the Incheon Strategy/SDG indicators when and where they are not collected and take measures to ensure disability is considered from the outset. This requires financial and staff resources to undertake the following:

   a. Complete a robust review of census and other surveys that are part of the national statistical system to determine what SDG indicators can be produced.
   b. For indicators that cannot be produced, make a determination of the most appropriate data tool to collect that data.
   c. Develop and add questions to collect the data necessary to create the indicator.
   d. Conduct a similar exercise for administrative data used for indicators.

3. Ensure that disability indicators are included in the core data systems, such as the census and ongoing surveys. Adding those questions will allow for the disaggregation of all Incheon Strategy or SDG indicators that are produced from core data systems.

4. Ensure that disability indicators are functionally in-line with the UNCRPD and the UN Statistics Commission recommendations, for example the WG-SS questions, which have been recommended by the CRPD Committee, the United Nations Special Rapporteur on the rights of persons with disabilities, various UN agencies, the UN Statistics Division for 2020 round of censuses, and development partners. Additional information can be found here.

Provision of technical assistance and capacity building to NSOs

1. Provide funding for technical assistance and capacity building to NSOs to support necessary modifications to data systems to produce and disaggregate key indicators. This should be tailored to local needs and capacities, and can include:
    - Establishment of working groups and peer exchange opportunities to enable south-south cooperation, for example, the Washington Group's regional groups, which already exist in the Pacific and Central Asia regions.
    - Targeted workshops with NSOs and key stakeholders, including persons with disabilities and other data users, across the collection, analysis, interpretation and reporting of data.
    - Country-specific technical assistance via expert consultant and/or coaching.

2. Conduct research that further examines the reasons why data systems have not been modified to include the indicators and the information needed to identify the population of persons with disabilities. This will allow more targeted technical assistance.

Invest in the capacity of OPDs to understand, use and advocate for quality disability data

Better disability data serves to inform policy and programming on supporting persons with disabilities. Organisations of Persons with Disabilities and their civil society partners have a critical role in raising awareness, supporting collection, analysis, interpretation and reporting of data, and holding duty bearers to account for the rights of persons with disabilities. Doing so requires them to have the ability to analyse and use available data, and make recommendations for improvement.

1. Provide open access to practical introductory disability data workshops for OPDs that promote national dialogue and are widely available across the region in various languages.

2. Develop a supplementary capacity development package that builds on the introductory training for individuals across the disability movement with higher-level interest and engagement in data. This should include training materials and a regional peer support and exchange network on disability data amongst OPDs.

3. Advocate and budget for OPDs roles in all data processes.

4. Involve and budget for persons with disabilities and their representative organisations to be involved in planning, implementation and monitoring of the CRPD and SDGs, as well as response and recovery efforts.

Investing in data that identifies the reasons for disparities in disaggregated data

As countries are increasingly able to produce development indicators and disaggregate by disability, it will be important to understand the key issues contributing to any disparity identified. This will help identify policy and programme levers to close the gap in, for example, access to employment, education or health services. Environmental factors are broad and far reaching, including the built and physical environment, the provision of services, attitudes, laws and regulations.

1. Support communities to gather community-generated data to complement traditional data sources and highlight information that cannot be captured in other ways.

2. Undertake case studies on what data is needed to identify environmental barriers and facilitators to help address the gaps identified when data has been disaggregated by disability. This includes data on, for example, the built environment, the provision of services and access to assistive devices, attitudinal barriers including stigma and discrimination, as well as policies and laws.

3. Support the fielding of targeted disability surveys to collect more detailed disability specific information. This goes beyond what can be expected in core data systems and includes information on barriers and facilitators to participation in things like education, employment, receipt of government services, political participation and family formation.

In summary, action is required by all stakeholders to expand the range of indicators that are produced and to ensure that recommended disability concepts, measurement tools and indicators are incorporated into all major data collections.

Building awareness and capacity and providing technical assistance and funding for quality data collection, analysis and dissemination requires investment. There is a need to mobilise more resources towards disability data. Doing so will ensure governments have the information to plan, adopt and evaluate targeted policies and programmes, and ensure information is available to track progress and promote accountability.

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This project was implemented as part of the We Decide Programme, which is a revolutionary initiative for promoting the principle of ‘nothing about us, without us’. It addresses gender-based violence (GBV) and promotes access to sexual and reproductive health and rights (SRHR) services and information for women and young persons with disabilities. We Decide was built on the disability-inclusive work at UNFPA with a purpose of making it more systematic and human rights based. The We Decide Programme has been generously funded since its launch in 2016 by the Government of Spain. It has been implemented on global, regional and national levels across UNFPA.

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