Talk by Sophie Mitra at the COSP 16 side event on June 16th 2023 on Zooming in on the human rights of persons with disabilities: launch of the DDI 2023 report

Hello everyone,

The script of this talk is on the website at the link that is in the chat box.

Thank you, Ambassador Rainne, for this introduction and for chairing this side-event of COSP16.

I am a woman in my 50s with grey hair, white skin, wearing a pink blouse and happy to be here with you.

What I am going to present is the work of a large team based in different parts of the world. First, I would like to acknowledge my coeditors, Jill Hanass-Hancock, GVS Murthy, Michael Palmer, Monica Pinilla-Roncancio, Minerva Rivas Velarde. This is also the work of several research assistants and contributors to the data analysis. I would like to highlight the work of Katherine Theiss, PhD student at Fordham University, who analyzed much of the microdata. I am also very grateful to the steering committee for strategic guidance and feedback on the report and to the Wellspring Philanthropic Fund for funding.

I will share with you the key findings from the 2023 report. It is on the Disability Data Initiative website. The link is in the chat box and I will read it out loud: **https://disabilitydata.ace.fordham.edu/**

The report is in three parts with the key findings in the main text, and selected country findings under Country Briefs. For each country, comprehensive results are in big Results Tables in an excel file. I am not going to use slides. A couple of times, I will share my screen to highlight tables and figures on the website and links will be in the chat box.

As background, since 2006, 186 governments have adopted the Convention on the Rights of Persons with Disabilities (the CRPD). And in 2015, governments have adopted the Sustainable Development Goals, a policy agenda promising to leave no one behind.

The Disability Data Report has two main objectives.

First, it reviews what data is available to identify persons with disabilities all over the world so that we know to what extent persons with disabilities are potentially visible and accounted for in national statistics. I say 'potentially' because the fact that disability data is collected does not necessarily mean that it is analyzed and used.

In fact, we already know that statistics on human rights and development continue to be very rarely disaggregated by disability status.

Is it because the data is not collected? That is the first question we try to answer.

Then we focus on countries that collect disability data and answer the question: what is feasible in terms of disaggregating indicators? Is it that the data is collected but perhaps does not lend itself to disaggregation by disability status?

Finally, we analyze the data and we have findings on the share of adults with disabilities and on disability disaggregated indicators at national and subnational levels in 15 countries.

Producing both national and subnational statistics on the situation of persons with disabilities is important because the CRPD may be a tool used by national as well as local governments to make their policies inclusive of persons with disabilities. In fact, even in countries that have not ratified the CRPD like the U.S., subnational estimates can inform policies as some local entities use the CRPD to uphold disability rights.

Recent evidence also shows that the COVID-19 pandemic and the climate emergency have had varied effects depending on geography and that persons with disabilities are more at risk during disasters and extreme climate events due to a lack of inclusive planning, accessible information, early warning systems and transportation, and due to discriminatory attitudes. Producing local disability statistics can help inform local policies and programs.

So first, regarding our review of datasets, this Report examines the questionnaires of close to 1300 datasets from 188 countries to identify those with functional difficulty questions, for example questions on difficulty seeing, hearing, walking, concentrating or remembering.

Why functional difficulty questions? Because functional difficulty questions follow the United Nations guidelines for disability measurement in censuses.

We also specifically track surveys and censuses that use the internationally comparable and tested Washington Group Short Set (WG-SS) which has questions related to difficulty seeing, hearing, walking, concentrating/remembering, selfcare and communicating. The WG-SS enables the monitoring of disability rights and the production of internationally comparable statistics.

What do we find?

1. About one in five of the datasets reviewed for the 2009-2022 period have functional difficulty questions.

2. 125 countries were identified as having at least one dataset with functional difficulty questions, including 70 countries with at least one dataset with the WG-SS. This is progress!

3. In fact, global trends suggest an increase in the share of datasets with the WG-SS in national censuses and surveys during the 2010s. However, in the early 2020s, High Frequency Phone Surveys rolled out by countries and international organizations during the pandemic often did not include the WG-SS.

4. Results also show considerable variation in the collection of functional difficulty questions across world regions. For instance, in Europe & Central Asia, functional difficulty questions continue to be rare in surveys and censuses, while in Sub-Saharan Africa, Middle-East and North Africa and East Asia and the Pacific, their availability has markedly increased.

   As a result, despite progress, there is still a need for more data collection in countries where data is lacking and in countries where we find data but such data is yet to be collected on an ongoing basis.

So we recommend that:

a. It should become standard for questions on functional difficulties such as the WG-SS to be included in national surveys and population censuses, including during emergencies such as pandemics to track the inequalities persons with disabilities experience and to inform and monitor policies.
b. In some countries, more resources may be needed to strengthen the national capacity to collect functional disability data through surveys and censuses.

Now, for countries with data, what can be done with it? I will now move onto our analysis of data in 15 countries to explore the potential to disaggregate indicators by disability status at both national and subnational levels.

I will start with a bit of background on the method we use. Persons with disabilities are a diverse group in so many ways, for instance in terms of disability type, degree, gender, age and where they live.

In terms of the degree, disability statistics on prevalence and inequalities can be estimated using different cut-offs on the degree of functional difficulties based on the WG-SS. The four point answer scale for each question is: no difficulty, some difficulty, a lot of difficulty and unable to do.

For instance, one could have two groups: persons with no and some difficulty together and then persons with a lot of difficulty and unable to do in another group.

We show results in gigantic and perhaps scary-looking tables using three ways of categorizing disability. But the way we find the most informative is to distinguish three groups: persons with no difficulty, persons with some difficulty and persons with a lot of difficulty or unable to do.

In cases where sample sizes are small for the disaggregated analysis, for instance when we compare people with different types of disabilities with survey data, then we contrast persons with no difficulty to persons with any level of difficulty (that is some, a lot or unable to do all together).

To get a sense of the size of the disabled community, we also consider persons with any level of difficulty (some, a lot or unable to do): based on our research in many countries, persons with some difficulty are also at risk of deprivations and exclusion and therefore should be considered as persons with disabilities.

So, we analyzed Demographic and Health Survey (DHS) data for 12 countries: Cambodia, Haiti, Maldives, Mali, Mauritania, Nigeria, Pakistan, Rwanda, Senegal, South Africa, Timor-Leste and Uganda.

We also analyzed census data for 3 countries: Guatemala, Kenya and Tonga.

What do we find in terms of what is feasible for disaggregation?

1. We show that it is possible to produce disability disaggregated indicators at the national level ***as well as*** at the regional level to document within country inequalities and for intersectional subgroups of persons with disabilities: males, females, rural and urban residents and by age group.
2. With census data in three countries, indicators could be disaggregated based on disability and for intersectional groups, at national, regional levels ***as well as*** at the district level.

What are the implications of these results?

a. DHS and population censuses should be regularly used to document and understand the inequalities persons with disabilities experience at national and subnational levels overall and for subgroups by sex, rural/urban residence and age.

b. Another implication is that a lot more disability disaggregated indicators could be produced. Many of the datasets in the 125 countries that have at least one dataset with functional difficulty questions are designed to be representative of their populations at both national and regional levels. So datasets that were not analyzed in this Report should be explored for their potential to produce disability disaggregated indicators at subnational levels.

c. Finally, national governments and international organizations need to allocate on-going resources and capacity building towards disability data analysis for national statistics offices and other stakeholders to analyze a growing body of data that can produce disability disaggregated statistics at both national and subnational levels.

Now, let me share a few of the results from the data analysis. Let's start with the share of adults with functional difficulties

1. First, at the national level, the share of adults with any difficulty ranges across countries from 12% in Cambodia to almost 33% in Uganda.

2. Within countries, the share of adults with functional difficulties does vary from region to region, but it is significant (that is above 5%) in the regions of the 15 countries. In other words, persons with disabilities are geographically spread out within countries. They are not highly concentrated in certain regions and absent in other regions.

I will share on my screen Table 1 in the Kenya Country brief. It is available at the link in the chat box:

https://disabilitydata.ace.fordham.edu/kenya/

The national share of persons with disabilities stands at 12.7%.

Seeing and walking difficulties tend to be the most common types of difficulties at both regional and national levels.
For example, in the Baringo region, 10.2% of adults have functional difficulties, and 5.5% have seeing difficulties.
Scrolling down, in Nairobi, the share in adults with difficulties is at 8.2%, while in Migori it is at 16.7%

What are the implications of these results for policy and research?

a. Disability rights as per the CRPD need to be upheld within countries in all regions, districts and villages.

b. Local policy making in general, and in various sectors from education to poverty reduction, needs to be inclusive of persons with disabilities and take account of disability inequalities across and within geographies.

c. We need more research on the variation of the share of persons with functional difficulties within countries to find out the extent to which demographic factors, resources, and environmental factors contribute to the variation.

Last but not least, what do we find on disability gaps or inequalities when analyzing disability-disaggregated indicators?

Key findings

1. We calculated the share of persons who are multidimensionally poor, that is persons who experience several deprivations such as having low educational attainment, not being employed, not having adequate living conditions such as poor quality flooring or not having electricity. The multidimensional poverty rate among persons with functional difficulties in the 15 countries, is consistently high that is above 50% at both national and regional levels.

2. We find an association between multidimensional poverty and the degree of functional difficulties within all countries. In other words, persons with some difficulty have higher poverty headcounts than persons with no difficulty, but lower rates of multidimensional poverty than persons with at least a lot of difficulty.

I will share on my screen maps for Guatemala available in figure and table formats at the link in the chat box:
https://disabilitydata.ace.fordham.edu/guatemala-2/
The map to the left is the multidimensional poverty rate for persons with no difficulty, the one in the middle is for persons with some difficulty and the one to the right is for persons with at least a lot of difficulty. The darker colors in the map in the middle and to the right illustrate how multidimensional poverty is more common as the degree of functional difficulty increases. This pattern is found in all regions of Guatemala, including in remote regions in the North.

This finding is also found at a more local level, at the municipality level, and is illustrated in maps on the disability gaps in the report, which I will show briefly and is at the link in the chat box:
https://disabilitydata.ace.fordham.edu/indicators-disaggregated-by-functional-difficulty-status/

3. Among persons with disabilities, women, older adults and people in rural areas have on average higher multidimensional poverty headcounts than men, younger adults and people in urban areas respectively.

4. For some indicators, results suggest that disability gaps are consistently experienced across and within countries. This is the case for educational attainment and multidimensional poverty.

5. For other indicators such as having safely managed water in a household, results on disability gaps do vary across and within countries. Within countries, national estimates can hide heterogeneity at the regional level.

What are the implications of these results in relation to the inequalities persons with disabilities experience?

   a. We need more research and data analysis, including mapping exercises to zoom in on the human rights situation of persons with disabilities at the local level. The barriers

persons with disabilities face and the resources they have such as access to assistive technology and information vary across geographies and may contribute to diverse inequality and human rights outcomes within countries. Understanding these drivers of inequality as well as enablers of inclusion is important to inform policies to reduce disability gaps

b. Policies, programs and practices, no matter where they take place within a country, need to be inclusive of persons with disabilities.

c. At both national and subnational levels, persons with disabilities and their representative organizations should be included in policymaking.