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Bonnie: Welcome to Included, the disability equity podcast brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I'm Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

Nick: I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. On this episode of Included, we sit down with Sophie Mitra, professor in the department of economics, co-director of the disability studies program, and founding director of the research consortium on disability at Fordham University. Dr. Mitra's research interests relate to disability health and wellbeing.

She has published in journals in economics, public policy, public health, developmental studies, and disability studies. She is a fellow and vice president of the human development and capability association and the principle investigator of the disability data initiative. She's a fellow of the Human Development and Capability Association, a Fordham Columbia research fellow, and an affiliate of the Columbia China Center for social policy.

[Music 01:38 - 01:45]

Nick: Dr. Mitra, thank you so much for joining us today.

Dr. Sophie Mitra: Thank you so much for having me.

Nick: Dr. Mitra, in your work, we've looked, previously, and we've seen you talk about this disability data initiative. We'd love if you could give our audience a broad overview, perhaps, of what that initiative is and why it's so important.

Dr. Sophie Mitra: Sure. Thank you so much for your interest in the disability data initiative. It was launched in June, earlier this year. It's important because many countries have developed national policies and legislations towards implementing the United Nations convention on the rights of persons with disabilities. In fact, 182 countries have, so far, ratified the CRPD, the convention. We need to know if the rights of persons with disabilities have been realized. If they have been realized in some countries, how is it that they were realized? What is it that worked? These questions are very difficult

to answer. To answer these questions, we need to collect and analyze data. Now, there are different ways to collect and analyze data that can inform policy on disability rights. One option is collect environmental and policy data to identify changes that are required in terms of barriers in the physical and social environment. Another option would be to collect qualitative and participatory data involving several stakeholders, people with disabilities, disabled people, and organizations, for instance.

These options, in terms of data collection, they go a long way in understanding the situation of persons with disabilities and informing advocacy and policy efforts. They do not provide nationally representative information on individuals in households with disabilities. They may be very difficult to compare across countries. This is where national statistics come in, and national statistics are based on household surveys and censuses that are nationally representative. They can provide estimates for indicators that document whether equal rights have been respected in a country.

For this, we need to have statistics based on concepts that are in line with human rights approach to disability, statistics, that can be desegregated by disability status, and that can reflect various aspects of the lives of people with disabilities, as well as their diversity in terms of age, sex, disability type, residents, and more. This need for such statistics has become even more important, during the pandemic, when disability prevalence may have increased and when disability and inequalities may well have been exacerbated.

For these reasons, the disability data initiative was developed to provide a systematic analysis of what is, often, a source of national disability statistics, so that is national censuses and household surveys, globally. The disability data initiative takes advantage of the increasing availability of internationally comparable and disability questions by analyzing the data for 41 countries, so data from censuses or surveys, and to produce close to 30 indicators desegregated by disability status.

Bonnie:

Thank you. This is so needed, and I'm really grateful that you're here to share this important work. You recently released the first disability data report. We're curious about your findings on the availability and quality of the data. Can you share a little bit about that?

Dr. Sophie Mitra: What we did is that we reviewed the questions related to disability in national censuses and surveys. Are there any disability-related questions, at all, in a survey? If we did find questions, what kind of questions were included? Based on that review of close to 1,500 data sets, we could say that disability questions, of any kind, were absent from 24 percent of countries.

Close to one in four countries had no disability-related questions in the censuses and surveys we reviewed. Sixty-five percent of surveys and censuses had no disability questions whatsoever. That's the first finding, suggesting that people with disabilities remain, to a large extent, invisible in national censuses and surveys.

Another interesting finding is that, when we did find disability-related questions, the general question that asks people, "Do you have a disability?" that question remains commonly found in censuses and surveys. Although, we know, from large literature in the past 20 years, that this general question—do you have a disability—does not produce meaningful and internationally comparable data. Disability may mean different things to different people. When they answer such a question, it's unclear what exactly we capture.

Also, disability is often stigmatized. Therefore, survey respondents may not feel comfortable answering this general disability question and may just answer no. Although, perhaps they do have a disability. There has been progress in terms of knowing how to ask questions on disability to avoid a bias related to stigma or to avoid using words that could mean very different things in different context. Progress has come from a lot of work done by the Washington group on disability statistics for the past two decades.

There are, now, international standards for disability questions in censuses. They're a part of the United Nations principles and recommendations for population and housing censuses of 2017. According to these recommendations, censuses need to ask questions about functional difficulties in at least four core domains: seeing, hearing, walking, and cognition.

That means people are asked, "Do you have any difficulty seeing?" even if you wear glasses, for instance. The recommendations also include two additional domains for self-care and communication. According to these United Nations recommendations, then functional difficult questions are the way to collect data in censuses. This is what we used to review the data sets. When we

found questions that met these United Nations recommendations, we considered the data set to have international comparable disability data. We found that only 84 countries, out of 180 countries, reviewed, and 16 percent of the surveys and censuses reviewed had these internationally comparable questions on functional difficulties. Of our own theories, there's still a lot of work to do in terms of collecting data through censuses and surveys to monitor the convention on the rights of people with disabilities, but also to monitor the sustainable development goals for people with disabilities.

Bonnie:

Yeah, thank you for sharing that. This is a question I think about, all the time, in my work, measurement of the assessment of disability and the questions. I just wanna ask a question that isn't on our list to you, but I'm curious about your thoughts 'cause it's come up so frequently. In this process of thinking about how we ask about disability and surveys. Asking someone if they identify as having a disability is, as you're indicating, something different, altogether, than, for example, the Washington questions you just described. Do you have serious difficulty seeing even while wearing glasses? Those types of questions.

Do you think, though, there's merit or value to, in addition to those kinds of questions, still asking about disability identity, acknowledging there's stigma and there's variation, across settings, context to better understand disability identity and how people are coming to that? That word, the community; there's a change in the community and certain places. Do you think there's value to start to think about adding an additional question about identity?

Dr. Sophie Mitra:

Yeah, I think there is value to a question using the term disability and to see how many people identify as having a disability. It would be interesting to compare what you get with such a question compared to what you get with the functional difficulty questions. In terms of comparing results from country to country, I think we're better off using the functional difficulty questions because they've been tested in different contexts across the world.

They work in different contexts, whether we're talking about a low-income country with an agrarian economy where, mostly, people are in rural areas and have agriculture jobs, or whether we are talking about an urban high-income country context. Do you have a disability? Yes, that gives us, I think, useful information in a given context at a given time to see how people self-identify.

Nick:

It's a super interesting question, the duality of these two different measures and what they mean. There's a lot of intersection with cultural aspects there that—I'm sure we could talk, for hours, about this, actually. I know Bonnie can, actually, to be honest with you.

Dr. Mitra, I'm gonna ask you a doozy of a question now. This report is so comprehensive. When I sat down to read it, I was just blown away by not just the data initiative, which already blows me away, but there was just so much that came out of it. I was wondering if you could give us your opinion, an overview of the main findings, perhaps some of the more striking findings or more important findings in your view.

Dr. Sophie Mitra:

Sure. Yes, the report is a little overwhelming in terms of the quantity of results it has. Yeah, so I can summarize some of the key findings of the analysis of survey and census data. We analyzed survey and census data for 41 countries, 41 countries that we have found to have national surveys or census data with the functional difficulty questions I talked about before. We have some results on prevalence rates and on inequalities for a bunch of indicators.

First, regarding prevalence, we find that functional difficulties are not rare. Across the 41 countries, the median share of the adult population with any functional difficulty is at 13 percent, which is quite close to the 15 percent global estimate of the world report on disability by WHO and the World Bank in 2011. When it comes to households—considering the share of households with at least one adult with a functional difficulty, the median share, across countries, is at 28 percent. More than one in four households have a functional difficulty.

These findings are important because they go against the common belief that persons in families with disabilities are a small minority. They're consistent with earlier prevalence estimates of using data from the early 2000s, using the World Health Survey data. That's, I think, one important result on prevalence rates.

Second, the report finds that there are significant inequalities associated with disability in terms of educational attainment, work, health, and standard of living. Standard of living, I mean living conditions such as housing or having electricity. We produced estimates of a disability gap, which is a disadvantage for persons with functional difficulties compared to persons with no difficulty. We did find a consistent disability gap, across countries, in terms

of educational attainment, literacy, food insecurity, exposure to a shock recently, asset ownership, and health expenditures. For majority of countries, we also found a disability gap for the employment rate, the youth adult rate, the share of adults in informal work, domestic violence, and living conditions.

Inequalities associated with disability were found for most of our indicators and across the different domains of wellbeing we considered. We also did a multidimensional analysis by looking at individuals and the extent to which individuals experience multiple deprivations or, at the country level, considering, on an indicator, by indicator basis, how many disability apps we found.

Again, here we found large inconsistent inequalities across countries. Another reason I'd like to highlight is a graded association we found between functional difficulty and disadvantage. When persons answer, "Do you have a difficulty seeing?" the answer scale in most of the countries we considered is a graded scale. People can answer some difficulty or a lot of difficulty or unable to do. We found that persons who answer some difficulty are worse off than persons who answer no difficulty, but they're better off than persons with at least a lot of difficulty.

That made us conclude that the group of persons with some functional difficulties should not be ignored in research and policy and that it's important to collect data on functional difficulties with a graded answer scale and not with yes/no answers. Perhaps a last reason I like to highlight is that we present indicators by type of functional difficulty. While we find inequalities for all types of functional difficulties—so seeing, hearing, self-care, and more—the largest gaps were for adults with self-care and communication difficulties.

Overall, our results point out how common functional difficulties are in countries around the world and that they are associated with large inequalities and that policy work is needed to curb these inequalities and to realize the convention on the rights of people with disabilities. The inequalities are stark, and we need policies and education, employment, healthcare, and social protection.

Bonnie:

Thank you. I really appreciate the lens of inequality on this report and looking at the data. I think, right now, there's such a focus on talking about equity. I'm just so grateful for the timing of this report, honestly. It really helps, in my mind, to elevate the need to include disability in those discussions. Thank you for this really important work. What do you see of the future implications of this

data and the impact on policy, moving forward? This is such a robust report. What does the future hold, based on your findings?

Dr. Sophie Mitra: Well, first, regarding data collection, our findings suggest that, at the national level, there's much work to be done to implement the CRPD. The CRPD has an article, article 31, that requires state bodies, "To collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the present convention." There's much work to be done to make this article 31 on national data collection a reality.

Bonnie: Can you just share, with our audience—sorry to interrupt—what CRPD stands for? I just wanna make sure our audience knows that.

Dr. Sophie Mitra: Yeah, CRPD's the Convention on the Rights of People with Disabilities. Many countries' national surveys or censuses do not provide the data that is necessary to monitor the CRPD. We need to have questions on functional difficulties as the United Nations guidelines recommends, so questions such as the Washington group [*unintelligible 21:31*] included in national surveys and censuses.

As far as the results of our data analysis goes, we do find sizable prevalence rates for functional difficulties. We need to pay attention to these prevalence rates and the extent to which some of these functional difficulties might be preventable through policies that either address underlying health conditions or environmental barriers.

Then, of course, the inequalities we find highlight the urgent need for policies for the rights and the wellbeing of people with disabilities and, notably, the need to monitor and implement the convention. The convention was ratified, promptly, by many countries, 182 countries so far. Almost all countries around the world have ratified the convention, but much work remains to be done to monitor and to implement the convention.

Nick: Wow. A lot of implications and a lot—this is one of those conversations where I'm so grateful that you're doing all this and there's so much information you're providing. At the same time, in the back of my mind, I'm just thinking there's so much further to go. We just appreciate, so much, that you were willing to take the time with us today. Is there anywhere, Dr. Mitra, that our audience can go to just learn more about your work?

Dr. Sophie Mitra: Yes. The disability data initiative has its own website. I'll spell it out. It's disabilitydata.ace.fordham.edu. The website has the disability data report, which has the main findings I just went over. The website also has methods briefs and results tables for anyone who wants to know more about how we did the analysis and who wants a complete set of our results. Finally, we have country briefs for all the countries we've analyzed so far. Yeah, so this was the first report. We plan to issue a 2022 report in a few months. Thank you so much for your interest.

Nick: Thank you.

Bonnie: Yeah, thank you so much. This is an immense undertaking, but so, so needed. Thank you for being our guest.

Dr. Sophie Mitra: Thank you.

Bonnie: You have been listening to Included, the disability equity podcast, brought to you by the Johns Hopkins Disability Health Research Center.

Nick: Thank you to our Included podcast team and everyone that made this podcast possible, especially Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Ten by Twenty challenge grant.

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