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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 have a chance to 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 and health and wellbeing. She is published in journals in economics, public policy, public health, development studies, and disability studies. She is the principal investigator of the Disability Data Initiative. She's also a fellow and Vice President of the Human Development and Capability Association, a Fordham Columbia research fellow, and an affiliate of the Columbia China Center for Social Policy. Dr. Mitra, thank you so much for joining us today.

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

*Nick:* Dr. Mitra, your work has been seminal to understanding economic inequities among people with disabilities. Could you give our audience a broad overview of your work on disability and economic outcomes?

*Dr. Sophie Mitra:* Sure. The common thread of my research has been to document and understand economic insecurity and to assess policies that aim to combat economic insecurity. Regarding disability and economic outcomes, specifically in the Global North, there is much evidence that disability is associated with nonemployment and poverty, but that's not the case in the Global South. Perhaps, as a result, many governments and NGOs have paid little attention to disability-related inequalities. My work is focused on the Global South, although I also do some work on the U.S., where I live.

With collaborators in anthropology, public policy, public health, psychology, and sociology, we have produced evidence to document disability inequalities and to understand the factors

that drive them. We've documented inequalities in terms of school enrollment for children, educational attainment and employment status for adults, and household income. We've also shown a consistent pattern of individuals with disabilities experiencing multiple deprivations, meaning that they're experiencing multidimensional poverty. They are, say, not employed, and not with health insurance, so experiencing two deprivations, or more, at the same time.

That's not to say that all persons with disabilities are poor, but rather that the way our economic systems are currently set up, persons with disabilities tend to be more often economically disadvantaged. With my colleagues, I've also worked on the drivers of inequalities. For instance, whether persons with disabilities may be affected by job loss due to discrimination, or may have to quit their jobs after disability onset, perhaps due to inaccessible workplace or transportation system.

Another area of interest has been the efficacy of social protection programs, such as cash transfer programs, as tools to combat poverty for persons with disabilities. For instance, I studied the disability grant program in South Africa and its effects on poverty reduction. Finally, an economic outcome of interest has been consumption expenditures by individuals in households with disabilities who may have extra costs of living with a disability. These could be additional medical care or transportation expenses. For instance, in New York City, where I am now, if the subway's not accessible, then a taxi becomes necessarily for a person with difficulty climbing stairs, and that comes with substantial additional costs compared to the subway.

*Bonnie:* Thank you, Dr. Mitra. So interesting. One area that you've paid particular attention to in your work is on direct costs of disability. Can you clarify for our audience what indirect costs of disability are, what that means?

*Dr. Sophie Mitra:* Yes, sure. Direct costs are additional out-of-pocket costs. They could be out-of-pocket costs for transportation, just like the subway example I just mentioned, out-of-pocket costs for health care services, medications, help with daily activities, as well as disability-specific goods and services. Let's say that if I become a wheelchair user, and I purchase an electric wheelchair, that's a direct cost, and so will be the cost of adapting my home with a ramp or elevator. I would also consume more electricity for my electric wheelchair, so that will also be a direct cost.

Now, direct costs are different from indirect costs. Indirect costs include economic activities that have been given up entirely or to some extent, such as a job that has been given up by the individual with a disability or their primary care in the household. These indirect costs are sometimes called opportunity costs. People may become unemployed or switch jobs due to inaccessible workplaces, for instance, and that may lead to a drop in income as a result of this job switch. That dropping income would be an indirect cost.

*Nick:* I have to admit, I find this very useful because when I read work like yours—and I’m not a trained economist—I just have such a hard time sometimes *[laughter]* following the vocabulary that’s used.

*Dr. Sophie Mitra:* I know. I mean there’s a lot of jargon.

*Nick:* It is a lot of jargon, and sometimes in economics, too, the jargon that they use, sometimes you’ll hear something like “direct costs,” and you’ll think, “Oh, well, that means this,” and it doesn’t mean that at all.

*[Laughter]*

*Nick:* I think this paper was written in 2017, “Extra Costs of Living With a Disability: A Review and Agenda for Research.” This is a nice paper that you gave a broad overstroke of this area as well. Can you give us a summary of your main findings?

*Dr. Sophie Mitra:* Yeah. Thanks for asking. This paper, done with a great international team of researchers, provided a global literature review on the direct costs associated with living with a disability at the individual level and at the household level. We searched the literature and found only 20 studies on this topic, 20 studies conducted in 10 countries. The studies were predominantly from the Global North, and the studies consistently found sizeable costs, in particular, with respect to health care, transportation, and attendant care. Now, the costs varied, and they varied across studies, but even within studies, the estimates varied depending on the severity of disability, the age of the person, and the household composition, so they increased with severity and age, and higher costs were found for persons living alone or in small households. These are the main results.

*Bonnie:* So interesting. An interesting aspect of this paper is that you reviewed the limitations of the literature, and you also offer

this agenda for future work in this area. Can you review those limitations and future directions for our audience?

*Dr. Sophie Mitra:*

Sure. What we realized is that research, so far, is mostly in the Global North, so we pointed out how more research is needed in the Global South. Because the extra costs are very context-specific, they vary depending on the availability of goods and services and their prices, and the nature of barriers that people face in their environment. We also found limited research in terms of, well, a limited set of methodologies. We found that most papers used quantitative methodologies, and, in particular, a methodology called the standard of living approach. We reviewed the limitations of this approach in the paper. I'm not going to go into the details.

We argued that we need more quantitative evidence, but using a wider range of methodologies. We also need more internationally comparable data on disability, so that we can compare extra cost estimates across countries, which is hard to do when you have different disability measures used in different studies. For more qualitative studies to become possible, we need more data collection using tools such as the Washington Group short set of questions. We need that in mainstream surveys and in disability-specific surveys; mainstream surveys because they can help us find extra costs on general items, such as health care or electricity or transportation, and disability-specific surveys because they can help us estimate the costs of disability-specific goods and services, such as assistive devices.

Now, extra costs also need to be assessed in how they are affected by programs and policies, and we didn't find much on that. For instance, mainstream policies, such as universal health coverage, may be key determinants of extra costs, and there may be other policies, like making public transportation systems more accessible that could also impact extra costs, so linking the literature to policies and programs seems to be an important priority. In terms of methods, we also recommend the use qualitative and participatory methods, especially to investigate unmet needs and the consequences of extra costs. None of the studies had the participatory component, so we recommend that partnerships with disabled people's organizations, persons with disabilities, and disability researchers are needed to move the literature to find unmet needs and the detrimental impact of these unmet needs or of extra costs.

Last, but not least, we also note in the paper that extra costs have often been studied in isolation, while, in fact, they are

closely tied to wellbeing. We need to include them in the study of wellbeing. What do we mean by that? Finding low extra cost is not necessarily good news because it could reflect the fact that people may have large unmet needs due to unaffordability or the absence of markets for important goods and services, and particularly for those goods and services that may be important for people with disabilities, such as assistive devices, as I mentioned earlier.

In addition, the accessibility of the environment may prevent people from getting needed goods and services, leading to low extra costs. Studying unmet needs and structural factors would be ways to connect costs to broader issues of wellbeing 'cause, in the end, I personally believe that wellbeing should be the central consideration, and extra cost may be a barrier to wellbeing for some. Yeah, so linking wellbeing and extra cost seemed like another important way to continue the research in this field.

*Nick:*

Wow. You guys really laid out a roadmap, and I just have to say that I can see it in Bonnie's face right now that she's just dying right now with everything you're saying *[laughter]* because, obviously, Bonnie and I are colleagues. We talk all the time, and you're encapsulating a lot of themes that she touches base on a lot, and taking them even further: the ideas that we don't have enough data, we need standardized questions, but we also need qualitative involvement of participatory research, and how that can drive this.

I thought this was amazing by the way. I really enjoyed this aspect of your paper 'cause I know sometimes that researchers go a little overboard with saying phrases like, "We need more research," but you guys said it very nice, laid out the actual step-by-steps of what that research would look like. That's sometimes lacking in academic papers. *[Laughter]* I have to just ask a million dollar question too. Has anything changed or progressed, in your opinion, since this paper came out? I know research is slow, and it's a large, long arc, but I'm just curious.

*Dr. Sophie Mitra:*

Yeah, so I haven't searched the literature in depth myself, but speaking with a colleague who is currently doing that. Our study period ended in 2015, and it seems, since 2015, there have been dozens of studies on extra costs, which shows that the literature is growing, and is growing rather fast, and the issue is getting more attention. That's great news, and these studies are overall inducing to confirm that the extra costs of disability are sizeable. That's encouraging in terms of the literature that is expanding. Now, the

limitations that I've just mentioned, I'm not sure that they've been addressed. A lot of the work done recently seems to be still in the Global North, largely, and still focused on very few quantitative methodologies. I think there might still be a lot of work to do in terms of diversifying methods in our stakeholders for research, and extending, maybe, the scope of the research in terms of linking the study of costs to the study of wellbeing.

*Bonnie:*

Yeah. Nick is right. I love this conversation very much, and I've been so excited to talk with you because of it. It underpins this idea that we need more disability data infrastructure. We need disability data outside of the common lanes of what people think of where we should be thinking about disability data. You talk about transportation. That's something I think about a lot. Yeah, and I think your work has really showcased that need, so I am grateful and so excited about this conversation because of it.

What are your thoughts, and what do you think about this concept of direct cost of disability, and the impact for policy as it relates to antipoverty and social programs? What's that connection there for you?

*Dr. Sophie Mitra:*

Yeah. I think there are strong connections between the direct costs of disability and antipoverty and social programs. There are different ways, in fact, for disability extra costs to be incorporated in the design of such programs. I'll give you a couple of ways that, to me, seem really important. One way is in taking into account the extra costs of disability in the eligibility criteria of antipoverty and social programs. Such programs often have an income or a consumption expenditure threshold, typically an income threshold. Let's say that, well, since we are in the United States, if the poverty line is at \$30,000 for a family of four, and if this poverty line is used as an eligibility criteria for a program, then this line needs to be adjusted to reflect the extra costs of disability.

It may not be adequate for a family with a disability and some extra costs, so you would need to set the poverty line higher for families with a disability, as income may, to some extent, be diverted to cover extra costs. It should be taken into account for poverty measurement, but also for the poverty assessment that is used to qualify for antipoverty and social programs. Another important way to incorporate extra costs in such programs is in setting levels of benefits at higher levels for families with disabilities to compensate for the extra costs of disability. Otherwise, the benefits may not be adequate enough to lift families with disabilities out of poverty.

Finally, there should be programs that provide in kind benefits, so, for instance, free transportation cards or the provision of goods and services at reduced or no cost for families with disabilities. That would reduce extra cost. That's another way to deal with extra cost at the policy level, by reducing them, by making them free, or by subsidizing them for families with disabilities. The issue of extra cost is very relevant to antipoverty and social programs, to their designs and their efficacy.

*Bonnie:* Yeah. I wanna ask a follow-on question because this is something I also think a bit about, although I'm not the expert you are in this space. Why do you think, at least in the United States, we haven't quite gotten there with some of these policies to what you just described? Right? Is it a lack of evidence? Is it a lack of understanding of the disability community? Why haven't some of these programs made some change to recognizing this indirect cost of disability and responded to meet that? Yeah.

*Dr. Sophie Mitra:* Yeah. That's a tough question. *[Laughter]* I'm not sure why there hasn't been much progress in the U.S. I think the lack of evidence is there. I think we could produce more evidence when it comes to these extra costs in the U.S. and tracking them by type of disability and then by region, so we could do, certainly, a lot more. That would help building the case that these costs need to be taken into account when we revise our programs, or perhaps these costs need to lead to new programs.

I would say health care is a huge issue in the U.S. *[laughter]* when it comes to the extra cost of disability, and if we do not have a universal and affordable health care system, then we need to find other ways to help people in being able to meet those health care costs. Now, there are additional costs, transportation, care costs, and more, but yeah, I don't think I can answer your question as to why. I can see that, for us researchers, there's an opportunity, actually, to do a lot more when it comes to documenting these costs.

*Bonnie:* Yeah, I completely agree, and I appreciate your willingness to answer that big question, so thank you. Thank you. I very much enjoyed this discussion. I know Nick did as well. Thank you so much, Dr. Mitra, for being our guest and talking about this important topic. We really appreciate it.

*Dr. Sophie Mitra:* Thank you so much.

*Bonnie:* You have been listening to *Included: The Disability Equity Podcast*, brought to you by the Johns Hopkins University Disability Health Research Center.

*Nick:* Thank you for our *Included* podcast team and everyone that made this podcast possible, especially Kartik Daswani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten By Twenty Challenge grant.

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