

## Introduction

**Abstract** In low-income countries, there has been very little research on disability and its link to deprivations. Much of the research is recent, and research using traditional poverty indicators (e.g., consumption expenditures) paints an unclear picture on the association between disability and deprivations. This is important as the prevalence of health conditions and impairments is expected to rise with an increasing life expectancy and as more policies try to address deprivations in relation to disability. This book asks the following: How should disability be defined to analyze and inform policies related to wellbeing? What is the prevalence of functional difficulties? What inequalities are associated with functional difficulties? What are the economic consequences of functional difficulties? The empirical work is focused on Ethiopia, Malawi, Tanzania, and Uganda.

**Keywords** Disability · Functional difficulties · Poverty · Low-income countries · Africa

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In December 2016, the United Nations Educational, Scientific and Cultural Organization (UNESCO) published the profile of Richard Mukaga, one of six children raised by his single mother in the rural Namaingo District in Eastern Uganda where polio left him unable to

walk from age six.<sup>1</sup> In June 2016, The Guardian newspaper started a series of online articles on disability rights. Many were about the challenges faced by persons with disabilities in low- and middle-income countries (LMICs). It described them as being marginalized in their communities, excluded from work and among ‘the poorest of the poor.’<sup>2</sup>

This recent attention to disability is welcome from the perspective of the field of international development where disability has been a marginal issue. It is barely mentioned in landmark policy documents (World Bank 2006, 2017) and in textbooks (e.g. de Janvry and Sadoulet 2016). Governments in LMICs and international donors in high-income countries (HICs) rarely pay attention to it. The term ‘disability’ itself is unclear and conceptually elusive. What does it mean exactly? Isn’t it a subjective notion? If it is, how can it be studied and measured so as to inform policy? Internationally comparable data has been missing on disability, making it difficult to investigate the significance of the phenomenon. There is also the common perception that disability is an issue that has more relevance in HICs where, due to aging and better survival chances in case of injuries or health conditions, people’s lives are extended and may thus experience disability. This perception is also entertained by the presence in HICs of social safety net programs such as disability insurance programs, often criticized for the potential disincentive to work and poverty traps they might create for persons with disabilities.

How does Richard live in a low-income country (LIC)? In a setting where most people are poor and there is little in terms of a social safety net, are deprivations more acute and more common for persons with disabilities or is disability not so relevant?

In this book, I present new research on disability and wellbeing in four LICs: Ethiopia, Malawi, Tanzania, and Uganda. This book analyzes four large longitudinal household survey datasets in Africa collected as part of the Living Standard Measure Study. These datasets have the Washington Group short set of questions on disability (Altman 2016). This set of questions identifies six functional or basic activity difficulties (functional difficulties for short): seeing, hearing, walking, concentrating/remembering, selfcare, and communicating. For instance, for seeing, it asks if, due to a physical, mental, or emotional health condition, individuals experience any difficulty seeing even when wearing glasses.

## 1.1 MOTIVATION

This research is motivated by three main factors. First of all, there is very little research on disability in the context of LMICs, and LICs in particular. Much of the research is from the last decade or so. The seminal World Report of Disability (WHO-World Bank 2011) contributed some internationally comparable prevalence and situational analyses in 59 countries, including in some LICs. It showed that disability is not rare and is associated with lower educational attainment, lower employment rates, and limited access to health services. Some recent research in LMICs has consistently found that disability is associated with a higher likelihood of experiencing simultaneous multiple deprivations (multidimensional poverty) (Hanass-Hancock and McKensie 2017; Mitra et al. 2013; Trani and Cuning 2013; Trani et al. 2015, 2016). In contrast, some research using traditional poverty indicators (consumption expenditures and asset ownership) paints a mixed picture (Filmer 2008; Mitra et al. 2013; Trani and Loeb 2010).

Second, the prevalence of health conditions and impairments is likely going to increase in LMICs in the near future. Aging is on the rise because of epidemiological transitions, including increased life expectancy due to a reduction in mortality from parasitic and other infections (WHO 2016). At the same time, chronic and degenerative diseases (e.g. cardiovascular diseases) are becoming more common. People may survive conditions once fatal as the quality and accessibility of treatments and healthcare improve (HIV/AIDS). Hence, there is a need to study disability in LMICs.

Third, in the past decade, disability has received more attention in policies and programs worldwide and more knowledge is required to inform them. As of January 2017, 172 countries have signaled their commitment to protect the rights of persons with disabilities with the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) a decade after its adoption (United Nations 2006, 2016). Disability also explicitly features in the sustainable development goals (SDGs) of the Agenda 2030 (UNDP 2016b). In LICs, there are numerous advocates who work toward the empowerment of persons with disabilities and they tend to work in NGOs or disabled people organizations. For policies and programs in LICs, more knowledge is needed on topics as basic as the prevalence of functional difficulties and their association with wellbeing inequalities.

## 1.2 RESEARCH QUESTIONS AND SCOPE OF THE BOOK

This book presents an empirical analysis of disability and wellbeing in Ethiopia, Malawi, Tanzania, and Uganda. In resource-poor settings, the specific research questions addressed in this book are as follows:

1. How should disability be defined to analyze and inform policies related to wellbeing?
2. What is the prevalence of functional difficulties?
3. What inequalities are associated with functional difficulties?
4. What are the economic consequences of functional difficulties?

The analysis in this book is quantitative and limited to the analysis of large-scale household survey datasets. While other methodological approaches such as qualitative and/or participatory approaches are beyond the scope of this book, I do believe that these other approaches involving multiple stakeholders may assist in developing a deep understanding of issues around wellbeing and disability and complement the research in this book. Stakeholders include, of course, persons with disabilities who can contribute their expertise from lived experience. They could also include other stakeholders depending on the particular issue under study, including family members, community leaders, employers, service providers (e.g., social workers), policymakers, and advocates. This book does not attempt to cover the field comprehensively, nor does it provide a full account on disability, health and wellbeing in Ethiopia, Malawi, Tanzania, and Uganda. I do not cover important areas such as education, transition from school to work, and noneconomic aspects of wellbeing such as social relations. It does not cover the long-term dynamics of disability and wellbeing, as individuals are followed over a period of only two years.

## 1.3 BOOK OVERVIEW

The second chapter provides the conceptual framework of the book, the human development model of disability, health, and wellbeing. It is based on the capability approach of Amartya Sen. The human development model highlights, in relation to wellbeing, the roles of resources, conversion functions, and agency. It uses capabilities (practical opportunities) and/or functionings (achievements) as the metric for

wellbeing. Impairments and health conditions are considered as determined by, and influencing, wellbeing. I believe the model generates insights for this book and research and policy on wellbeing, disability, and health.

Chapter 3 introduces the empirical context of this study, from measurement to data and country contexts. This book uses nationally representative Living Standard Measurement Study datasets for Ethiopia, Malawi, Tanzania, and Uganda, which include six questions on functional difficulties. The four countries under study have ratified the CRPD with Disabilities and adopted national policies or legislations on disability.

Chapter 4 through 6 present the empirical analysis and results of the book. These chapters have sections covering the literature review, methods, results/discussion, and a summary of results. The methods sections are quantitative, and not all readers will have the inclination to read them. I have included statistical methods primarily in boxes that some readers may want to consult.

Chapter 4 presents results regarding the prevalence of six functional difficulties (seeing, hearing, walking, concentrating, selfcare and communication) overall and by functional difficulty type, severity, age at onset, age, sex, and socioeconomic status. It presents results on the use of assistive devices and healthcare services among persons with functional difficulties.

Chapter 5 focuses on inequalities that are associated with functional difficulties at a given point in time. Inequalities are considered for educational attainment, morbidity, work, household material wellbeing and economic security. Inequalities are also analyzed through multidimensional poverty measures.

Chapter 6 investigates three separate issues on the dynamics of functional difficulties and inequalities. It compares the wellbeing of persons with different trajectories in terms of functional difficulties; for instance, how do persons with persistent functional difficulties fare compared to persons with temporary difficulties? It also assesses if changes in functional difficulties are associated with changes in employment outcomes and assets/living conditions. It analyzes if functional difficulties are correlated with mortality in the short run.

The last chapter presents concluding remarks that summarize the main results and derive implications for policy and future research. It does not have all the nuances of the main text of each chapter and should be read with this in mind. Overall, it shows that disability needs

to be considered from multiple angles including aging, gender, health, and poverty. This book concludes that disability policies are unlikely to be conducive to human development for all if they *exclusively* use an oppressed minority group approach and focus on barrier removal. It makes a call for inclusion *and* prevention interventions as solutions to the deprivations associated with impairments and health conditions.

## NOTES

1. [http://www.unesco.org/new/en/education/resources/online-materials/single-view/news/disability\\_education\\_and\\_work\\_a\\_life\\_spent\\_fighting\\_for/](http://www.unesco.org/new/en/education/resources/online-materials/single-view/news/disability_education_and_work_a_life_spent_fighting_for/).
2. 'Mexico City from a wheelchair: There is no second chance from these streets' The Guardian Resilient Cities for the 21st century. Accessed on 23 June 2016 at: <https://www.theguardian.com/cities/2016/jun/23/mexico-city-wheelchair-users-disability-street-workout-athlete-abraham-plaza>.

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