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**Investigating disability-inclusion in social protection programmes  
in low- and middle-income countries, with case studies from  
Vietnam and Nepal**

**Lena Morgon Banks**

**Thesis submitted in accordance with the requirements for the  
degree of Doctor of Philosophy of the University of London**

**March 2019**

Department of Clinical Research

Faculty of Infectious and Tropical Diseases

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

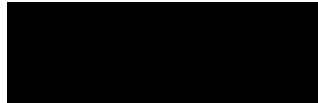
Funded by the Australian Department for Foreign Affairs and Trade (DFAT)

Research group affiliations: The International Centre for Evidence in Disability

## Declaration

I, Lena Morgon Banks, confirm that the work presented in this thesis is my own. Where data and information have been derived from other sources, I confirm that these have been indicated in the thesis.

Student signature:

A solid black rectangular box used to redact the student's signature.

Date: March 28, 2019

# **Abstract**

## **Background:**

Social protection is increasingly used by governments in low- and middle-income countries (LMICs) as a strategy for alleviating poverty “in all its forms”. People with disabilities are frequently targeted as key beneficiaries due to high levels of poverty and marginalisation. Little is known, however, on whether people with disabilities are accessing existing programmes, and whether these programmes adequately meet their needs.

## **Aim:**

To explore the need for, access to and adequacy of social protection amongst people with disabilities in LMICs.

## **Methods:**

Systematic reviews were used to compile and evaluate evidence from across LMICs on 1) the link between monetary poverty and disability, and 2) access to and impact of social protection amongst people with disabilities.

Case studies were then undertaken in the districts of Cam Le, Vietnam and Tanahun, Nepal in 2016 to explore in-depth the need for, access to and adequacy of social protection amongst people with disabilities in these areas. Data was collected through population-based surveys (n=12,397, across both settings), with nested case-control studies of people with and without disabilities (n=359, each) matched by age, sex and location. Further, qualitative research was conducted with people with disabilities recruited from the surveys and key informants involved in the design or implementation of social protection.

Need for social protection was assessed using monetary and multidimensional indicators of poverty amongst people with disabilities ages 15+. Access to social protection was measured through participation in disability-targeted and non-targeted programmes. Adequacy of social assistance was then evaluated by measuring levels of monetary and multidimensional poverty amongst social assistance recipients. All

analyses compared indicators between people with and without disabilities, and amongst people without disabilities (e.g. recipients versus non-recipients).

### **Key findings:**

Evidence from the systematic review and research in Nepal and Vietnam indicate a high need for social protection among people with disabilities. In the systematic review, 80% of the 150 included studies found a link between disability and economic poverty. In both Vietnam and Nepal, people with disabilities were more likely to be living in both monetary and multidimensional poverty compared to people without disabilities, and faced high disability-related extra costs.

People with disabilities in Vietnam and Nepal were more likely to access social assistance compared to people without disabilities (Vietnam: aOR 9.6, 5.6-16.5; Nepal: aOR 3.0, 1.6-5.3). However, evidence from the case studies and from the systematic review indicate that many people with disabilities are not accessing social protection benefits for which they are eligible. Factors affecting access included the accessibility of the application process, complexity of disability assessment procedures, awareness of programmes and their eligibility requirements and the perceived utility of benefits.

Further, the systematic review and research in Vietnam and Nepal indicated that social protection is often inadequate to protect many recipients with disabilities from poverty. For example, a quarter to a third of social assistance recipients with disabilities were living in monetary poverty and half were multidimensionally poor in Vietnam and Nepal. Social protection was particularly insufficient at promoting social inclusion amongst people with disabilities, as well as ensuring sustainable livelihoods.

### **Conclusion:**

People with disabilities face a substantial need for social protection, given high levels of monetary and multidimensional poverty, in both absolute terms and relative to people without disabilities. However, many people with disabilities were not accessing programmes for which they were eligible, indicating a need to increase awareness of programmes and address barriers encountered during the application

process. Further, evidence from this research indicates that more transformational approaches to social protection design and delivery are necessary, such as providing meaningful coverage for disability-related extra costs and addressing drivers of social exclusion.

## Format of the Thesis

The thesis for this PhD is presented in the ‘research paper style’ format, in accordance with the London School of Hygiene & Tropical Medicine research degree regulations. It includes several different but related journal articles that have been published in, accepted by, or submitted to peer-reviewed journals.

Chapters that are italicised in the Table of Contents are in the research paper format. Details of these publications, as well as acknowledgement of other contributors, are included in the “Research Paper Cover Sheets”. This thesis also contains linking materials to provide information not covered in the research papers and to ensure this thesis reads as a coherent body of work.

This thesis is divided into five sections (A to E) with each section sub-divided into chapters.

Section A includes the introductory chapters on disability and poverty (Chapter 1) as well as disability and social protection (Chapter 2). The study rationale, aims and objectives are then detailed in Chapter 3.

Section B presents evidence from across low- and middle-income countries on disability, poverty and social protection. This section comprises two research papers (Chapters 4 & 5), which review available evidence on disability, poverty and social protection. Both papers are systematic reviews, with *Chapter 4, Paper 1* exploring the relationship between disability and economic poverty and *Chapter 5, Paper 2* assessing access to and impact of social protection amongst people with disabilities.

Section C then explores new evidence generated through studies in Cam Le, Vietnam and Tanahun, Nepal. Studies in both settings involved population-based surveys with nested case-control studies, alongside qualitative research. In *Chapter 6, Paper 3* the need for social protection amongst people with disabilities was assessed by measuring levels of monetary and multidimensional poverty between people with and without disabilities in the study settings. *Chapter 7, Papers 4 & 5* then evaluates access to available social protection schemes in both settings amongst people with and without disabilities, as well as factors that affect access. Finally, *Chapter 8* explores the adequacy of social protection in meeting its intended

aims, by comparing monetary and multidimensional poverty in social assistance recipients with disabilities to non-recipients with disabilities and people without disabilities.

Section D presents a discussion of the findings from this PhD thesis. It includes a summary of the findings and their implications (Chapter 9) and the study strengths and limitations, and recommendations for future research (Chapter 10). Chapter 11 is the conclusion.

Section E includes the appendices.



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## List of Abbreviations

aOR: adjusted odds ratio

CHI: Compulsory Health Insurance

CI: confidence interval

CSI: compulsory social insurance

DDDC: Disability Degree Determination Council

DPO: Disabled People's Organisation

HUPH: Hanoi University of Public Health

ICF: International Classification of Functioning, Disability and Health

ILO: International Labour Organization

LMIC: low- and middle-income country

LSHTM: London School of Hygiene & Tropical Medicine

MDGs: Millennium Development Goals

MEC: Medical Evaluation Council

MPI: Multidimensional Poverty Index

NGO: non-governmental organisation

n.d.: no date

NPR: Nepali rupee

OR: odds ratio

PPP: purchasing power parity

PRISMA: preferred reporting items for systematic reviews and meta-analyses

SDGs: Sustainable Development Goals

SE: standard error

UN: United Nations

UNDP: United Nations Development Programme

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

USD: United States Dollar

VaRG: Valley Research Group

VDC: Village Development Committee

VHI: Voluntary Health Insurance

VND: Vietnamese Dong

VSI: voluntary social insurance

WASH: water, sanitation and hygiene

WHO: World Health Organisation

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## Contributors to the research presented in this thesis

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*Contributors to systematic reviews:* Sarah Polack, Rachel Mearkle, Islay Mactaggart

*Contributor to multidimensional poverty research:* Monica Pinilla-Roncancio, Oxford Poverty & Human Development Institute

*Administrative support:* Jyoti Shah

All photos displayed in this thesis were taken with written consent.



## **SECTION A      INTRODUCTION**

# Chapter 1. Disability and poverty

## 1.1 Defining disability

The United Nations Convention on the Rights of Persons with Disabilities'

(UNCRPD) defines disability as including people with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder full and effective participation in society on an equal basis with others” [1].

While conceptualisations of disability vary, the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) is a useful approach to understand disability and, in conjunction with the UNCRPD definition, will be used throughout this thesis [2]. According to the ICF framework (Figure 1), disability is the result of a health condition that, in interaction with personal and environmental contexts, leads to dysfunction at the level of body function/structures (impairments), the individual (activity limitations) and/or the individual within society (participation restrictions). The ICF model also includes environmental and personal contextual factors that may heighten or lessen experiences of disability. For example, a person with polio (health condition), may experience lower limb paralysis (physical impairment), which in turn can lead to difficulties in walking or self-care (activity limitations). This individual may also be excluded from school or work (participation restrictions), especially when combined with contextual factors such as inaccessible built environments, stigma towards disability or lack of access to an assistive device. Personal factors, such as education level and access to rehabilitation services, and environmental factors, such as policies on inclusive employment, may improve the level of participation.

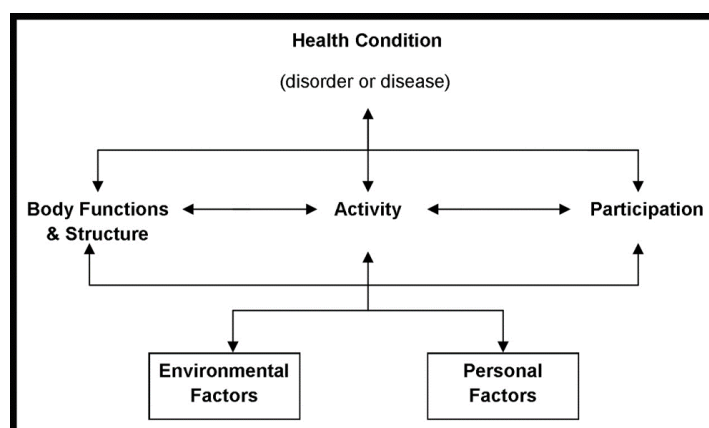


Figure 1 ICF Framework (Source: [icfeducation.org](http://icfeducation.org))

The World Health Organization and the World Bank estimate that 15% of the global population has a disability, amounting to over 1 billion people worldwide [3]. However

estimates on the prevalence of disability can vary widely, which is influenced in large part due to differences in conceptualising disability and in measurement approaches [4]. For example, prevalence measured through self-reported disability (e.g. “Do you have a disability?”) often generate low estimates due to stigma of disability or implications that “disability” represents a severe condition; these estimates may also not be comparable across time and place due to differing sociocultural interpretations of disability [4, 5]. In contrast, functioning-based approaches (e.g. “Do you have difficulty walking”) tend to generate higher estimates of disability prevalence that are considered more internationally comparable, as they ask about difficulties in performing specific everyday activities, which is less stigmatising or open to individual interpretation [6]. The World Health Organization and World Bank’s estimate of 15% global prevalence of disability is largely grounded in functioning-based approaches to disability measurement [3].

## **1.2 Defining poverty**

As with disability, poverty is a complex concept to define and measure. In its broadest definition, poverty can be described as “a state in which individuals or households show significant deficits in well-being” [7]. However, there is little consensus on a best approach for understanding and measuring poverty, despite the focus on poverty alleviation as a core aim in most national and international social and economic development policies and programmes [8, 9]. Different approaches have been used to measure poverty, including monetary, capability, social exclusion and participatory approaches, which are described in this section. These approaches are described in detail in Section 1.2, and then Section 1.3 explores considerations for using these approaches amongst people with disabilities

### *Monetary approach*

Historically, and continuing to today, poverty has most frequently been viewed as a shortfall in income or consumption [9, 10]. Monetary approaches define poverty as occurring when individuals or households have insufficient economic resources (e.g. income, savings, material assets) considered necessary to achieve an acceptable standard of living [9]. Often, a person or household’s available resources are measured against a defined level, below which they can be classified as living in poverty [10]. For example, poverty lines in many countries are based on the

minimum income deemed necessary to satisfy basic needs, through estimations of the cost of food and other necessities [11]. Individuals or households with income/consumption below this threshold are defined as being poor and may be targeted for poverty alleviation programmes.

Although many still recognise that monetary approaches to poverty are useful, major critiques have emerged. First, it has been increasingly recognised that the correlation between economic resources and well-being is not always straightforward [9, 12]. For example, income only predicts whether an individual can theoretically afford certain items or services, but does not capture whether these items are available or accessible to that person [13, 14]. While expenditures data more closely track actual spending and consumption, needs will vary by individuals and setting [13, 14]. As an illustration, possessing a certain level of income may not ensure that an individual is able to buy sufficient food if their setting is in the midst of a food shortage. Even if they have bought or produced food, it may not be sufficient, as calorie and nutrient requirements may vary between individuals based on lifestyle, age, sex and other factors. The translation of economic resources into access to other goods and services – such as healthcare and education – is even more tenuous [9]. For example, paying for healthcare is not a guarantee of being in good health or having received good quality services that meet the individual's health needs.

Second, monetary indicators may not capture all resources at an individual or household's disposal [15]. Income, for instance, is a particularly poor measure of material wealth in societies where barter or production of goods and service for personal consumption (e.g. subsistence farming) are common [16]. Similarly, measurement tools tend to focus on private resources, often overlooking social resources (i.e. goods and services that an individual may have access to due to their relationships with others, such as being able to borrow a friend's car or sharing food with neighbours) and publically-provided goods and services (e.g. school nutrition programmes, subsidised transport, education, healthcare) [9, 17]. Consideration of these resources can substantially alter assessments of well-being.

Third, accurately capturing all sources of income and expenditures can be methodologically challenging, as well as time consuming and costly [16]. For

example, respondents may be reluctant to disclose their income or expenditures to unfamiliar data collectors. Additionally, income and expenditure can be highly volatile over time. For instance, households may be engaged in a range of income-generating activities, which may be short-term or fluctuate in their returns, or receive gifts, remittances or aid at irregular time periods. Similarly, surveys on expenditures may not capture all sources of spending and prices may vary substantially over short time periods (e.g. due to seasonality, shortages). These issues present challenges not only for collecting accurate data, but also for making determinations of poverty. Often, measurements at one point in time are used as a proxy for average wealth, which may be misleading when fluctuations are extreme or frequent [18].

Finally, setting poverty lines is controversial. Notably, determining which basket of goods and services are essential, and their monetary values, is both methodologically challenging and often highly subjective [9, 11]. Further, many countries have a single national poverty line; however, prices, as well as what goods and services are essential, are likely to differ substantially by region and in urban compared to rural locations [18]. Even when multiple sub-national poverty lines are used, these are rarely adapted for individual factors (e.g. age, sex, lifestyle).

### *Capability approach*

Other approaches to conceptualising poverty have been advanced in light of these critiques of monetary approaches. For example, the capability approach pioneered by Sen conceptualises well-being as individuals' freedom to lead a life they value, and have reason to value [19, 20]. It focuses on an individual's "capabilities" and "functionings". Functionings describe different states that a person has succeeded in "doing or being" (e.g. being healthy, employed, nourished), while capabilities refer to the opportunities a person has to achieve these desired functionings (e.g. access to healthcare, decent work and food) [9, 19]. A classic example to differentiate functionings and capabilities concerns two people who are starving: one may have access to food, but is choosing to fast for religious reasons, while the other cannot afford food. These two individuals have the same functioning (starving), but differ in their capabilities (access to food). In the capability approach, resources such as income can be useful in achieving desired functionings, but they are considered insufficient as a measure of well-being because the ability to transform resources

into desired functionings will vary between individuals and societies [21]. This variation may be due to individual characteristics (e.g. health status, social relationships, age, gender) or contextual factors (e.g. living in areas where services are available, publicly provided) [9]. Consequently, directly measuring capabilities and functionings (e.g. level of health, access to healthcare) more accurately captures well-being in these areas, rather than using material wealth as a proxy (e.g. spending on healthcare, having enough income to afford health services).

Measurement of poverty using the capability approach focuses on deprivations in certain basic capabilities [20]. The content of this set of desired basic capabilities was not explicitly defined by Sen to allow for context- and purpose-relevant development of indicators [22]. Ideally, measures should focus on capabilities (e.g. ability to go to school) but in practice, achieved functionings are most often used as they are easier to observe (e.g. school attendance) [23, 24].

The capability approach also emphasises the importance of multidimensional poverty measurement. Multidimensional poverty indexes (MPI), particularly using the Alkire & Foster methodology, are often grounded in the capability approach [15, 25]. For example, the Global MPI has been used by the United Nations Development Programme since 2010 in its Human Development Reports to measure multidimensional poverty in over 100 countries [26]. Governments in several countries, particularly in Latin America, have also developed national MPIs that are tailored to capture locally-relevant measures of poverty [15]. Under the Alkire-Foster methodology, MPIs use a set of indicators (covering capabilities or functionings such as access to health and education and living standards) each of which have a deprivation cut-off below which an individual/household can be considered to be deprived [25]. Each indicator is given a relative weight so that the MPI sums to one (1=complete deprivation, 0=no deprivation). Deprivation scores generated are then compared against a poverty cut-off (e.g.  $\geq 0.33$ ). An individual or household may be classified as multidimensionally poor if the sum of their weighted deprivations falls above this line. The choice of indicators, their weights and cut-offs, and, in particular, the overall multidimensional poverty line cut-off, are defined through normative judgement – such as what are acceptable levels of deprivation and how important each indicator is to an individual's experience of poverty – which have been cause

for critique [25, 27]. To improve the validity of these choices, participatory and expert-based approaches are recommended [28]. Further, robustness testing – particularly the robustness in the rank ordering (i.e. comparison of poverty levels between groups or areas) – is also important for strengthening the utility of the MPI in informing policy decisions [29].

### *Social exclusion approach*

Most of the poverty measures discussed so far concern absolute poverty, in which indicators of deprivations are compared against a defined minimum level. Recently, however, there has been a shift from absolute to relative measures of poverty, particularly in high income countries [30]. For example, the European Union measures at risk-of-poverty as the proportion of people falling below 60% of national median disposable income in each year<sup>1</sup> [31]. This change to relative measures is reflected in the “social exclusion” conceptualisation of poverty, which recognised that as countries grew wealthier and put in place welfare systems to ensure its citizens could meet basic needs, marginalisation and deprivation still persisted [9, 30]. Most definitions of the social exclusion approach incorporate Townsend’s characterisation of poverty as occurring when an individual, household or group’s “...resources are so seriously below those commanded by the average family that they are in effect excluded from the ordinary living patterns, customs, and activities” [32]. Poverty measures using this approach are context-specific, as they focus on *relative* exclusion from social activities or rights, based on what is typically enjoyed by others in that setting [9, 33]. In addition to relative income poverty, multidimensional indicators, such as long-term unemployment, lack of access to services or poor housing quality, are often applied. The social exclusion approach is also more focused than other models on processes of exclusion, such as structural inequalities or discrimination against certain groups (e.g. ethnic, religious minorities, people with disabilities) [9].

A key concern with the social exclusion approach has been its applicability to LMICs, particularly settings where absolute poverty is high [9]. For example, low levels of education and insecure livelihoods may be the norm in certain contexts. Therefore,

---

<sup>1</sup> Equivalised and after social transfers

exclusion from decent work or education does not constitute social exclusion in those settings, even if it is recognised that these situations are undesirable or negatively impact well-being [9]. As a work-around, international norms or standards from high-income countries (e.g. minimum level of education) have been applied, although with some controversy [9].

### *Participatory approaches*

Measures of poverty using the capability and monetary approaches – and at times the social exclusion approach in LMICs – have been critiqued for externally imposing a definition of poverty without properly consulting with people who are living in poverty [9, 33, 34]. Consequently participatory approaches have been employed, whereby people living in poverty are central to defining what poverty means in their setting and how to capture it [34, 35]. Notably, this approach has been institutionalised by the World Bank and the International Monetary Fund as a required component of their Poverty Reduction Strategy Papers, which are part of a country's application for debt relief or aid [9, 35]. Participatory approaches have been used independently to describe poverty qualitatively or in combination with other approaches, such as MPIs, to define appropriate and context-relevant indicators of poverty [9]. However, by their nature, participatory approaches can limit comparisons of poverty across time and contexts [9].

#### **1.2.1 Risk, vulnerability and poverty**

Across conceptualisations of poverty, duration is a central concern [7, 9, 36]. Chronic poverty can be identified through its persistence over time, and can be measured using most of the previously outlined measures of poverty [36, 37]. Chronic poverty can be particularly difficult to escape and may lead to irreversible losses in well-being, even across generations [38].

Risk and vulnerability are important factors in understanding chronic, as well as transient, poverty [39]. Vulnerability describes the likelihood that individuals, households or communities will be in poverty in the future [7]. A key component of vulnerability is exposure to “risks” [40]. Risks are shocks or stresses, which if they were to occur, would have a negative impact on well-being [39]. For example, episodes of sickness, natural disasters and unemployment are all risks that may



directly lead to or worsen poverty, due to high spending on healthcare, loss of income or destruction of food crops and housing. Further, the strategies that households take to prevent or cope with these risks may indirectly contribute to poverty [39, 40]. For example, selling off productive assets to pay for healthcare or delaying seeking essential healthcare due to high costs are often unavoidable responses to sickness for households living in or vulnerable to poverty. However, these responses can have long-term implications on well-being and ability to escape poverty in the future.

People currently in poverty are highly vulnerable to continuing to stay in poverty, particularly due to the presence of “poverty traps”. People living in poverty are likely to have the highest risk of shocks and stresses, due for instance to unsafe working or living environments, unstable employment, poor nutrition and greater exposure to disease [40]. They are also likely to have fewer – or lower quality – resources and coping mechanisms available to prevent or mitigate the impact of risks if they occur [37]. For example, people in poverty may not have adequate income, savings, or access to health insurance and accident/injury cover. In addition to risk and vulnerability, chronic poverty may also be explained by adverse structural factors, such as discrimination and stigma towards certain groups [39].

A key challenge to measuring chronic poverty has been the lack of longitudinal data [7, 9, 36]. While studies using the capability and social exclusion approaches often only measure poverty at one time point, their measures may indicate risk of long-term deprivation [9]. For example, some measures such as malnutrition in childhood may have long-term impacts on growth and development, while low educational attainment can affect future livelihood stability and security. Still, it is recognised that more longitudinal poverty research is needed [7, 9].

### ***1.2.2 Poverty in the Sustainable Development Goals***

The Goal 1 of the United Nations Sustainable Development Goals (SDGs) seeks to “[e]nd poverty in all its forms everywhere” [41]. The SDGs represent an evolution in the conceptualisation of poverty from the predecessor Millennium Development Goals (MDGs), whose targets and indicators focused on a monetary approach to poverty (i.e. the proportion of people whose income is less than \$1 per day) [42, 43].

In contrast, the underlying targets and indicators for SDG 1 reinforce a commitment to addressing both monetary and multidimensional forms of poverty<sup>2</sup>.

Monetary poverty is the focus of Target 1.1, which aims to “eradicate extreme poverty for all people everywhere, currently measured as people living on less than \$1.25 a day” by 2030 [41]. This threshold<sup>3</sup> is considered as the international poverty line representing “extreme poverty” across contexts, with adjustment for purchasing power parity to account for differences in costs of living in each country [14].

Consumption per capita is the preferred source of data for monitoring Target 1.1, although income is also used [14].

In addition to the international poverty line, Target 1.2 addresses national definitions of poverty, across both economic and multidimensional forms. Indicator 1.2.1 measures “the proportion of the population living below the national poverty line, by sex and age”, while indicator 1.2.2 focuses on “poverty in all its dimensions according to national definitions” [41]. For the latter, several countries have adopted national MPIs to produce a single summary measure for tracking progress [14]. Similarly, Target 1.4 covers access to basic services, as well as land rights and financial services, to broaden the conceptualisation of poverty beyond monetary measures [41]. Target 1.5 then focuses on risk and vulnerability as a contributor to poverty. It aims to “build the resilience of the poor and those in vulnerable situations and reduce their exposure and vulnerability to climate-related extreme events and other economic, social and environmental shocks and disasters” [41].

Finally, SDG 10 focuses in-depth on inequality across social, economic and political domains. Targets and indicators in SDG 10 capture poverty in line with social exclusion approaches. This includes the use of relative measures of economic well-being, such as the “proportion of people living below 50% of median income...”

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<sup>2</sup> Going forward, this thesis will refer to monetary/economic and multidimensional measures of poverty. Economic/monetary measures include income, assets and expenditures. Multidimensional measures may include a range of indicators, such as access to education, healthcare, work and social participation, often displayed in MPIs.

<sup>3</sup> The international poverty line has since been revised to \$1.90 per person per day (international dollars, using 2011 purchasing power parity) [11].

(Indicator 10.2.1) and the focus on processes of exclusion such as “...discriminatory laws, policies and practices...” (Target 10.3) [44].

### 1.3 The link between disability and poverty

Certain groups may be particularly likely to experience poverty, as a result of greater risks and vulnerabilities. People with disabilities are a key group believed to be likely to experience poverty. For example, poverty and disability are often described as operating in a cycle<sup>4</sup>, with the one re-enforcing the other (Figure 2) [45, 46]. For example, conditions associated with poverty, such as inadequate safe water, sanitation and hygiene (WASH), lack of access to healthcare, malnutrition, and unsafe working and living conditions increase the risk of disability. In turn, disability is linked to exclusion from work, education and social life, as well as high spending on healthcare and other expenses, all of which can lead to or worsen both monetary and multidimensional forms of poverty [3, 47]. People with disabilities may be particularly vulnerable to chronic poverty, as they face high exposure to risks (e.g. unstable employment, greater likelihood of experiencing violence and abuse), but may have access to fewer coping strategies (e.g. fewer assets, lower access to financial services, smaller social networks) [3, 46]. Discrimination and marginalisation of disability further compounds vulnerability to chronic poverty.

While there is a strong theoretical basis for an increased risk of poverty among people with disabilities, empirical evidence validating and describing this association has been lacking [48, 49]. For example, a frequently cited statistic states that people with disability as twice as likely to be living in poverty compared to people without disabilities [3, 49]. However, upon tracing this statistic to its source, it was found that the evidence supporting this figure was decidedly weak [48].

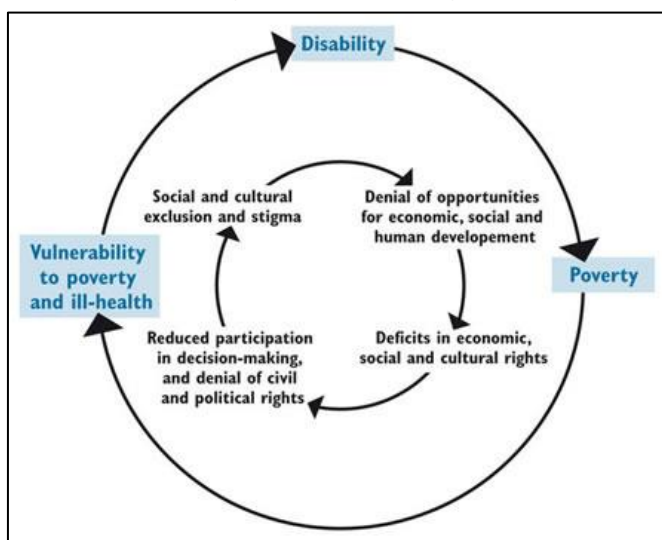


Figure 2 Disability-poverty cycle (DFID, 2002)

<sup>4</sup> This thesis will be focusing on the increased risk of poverty among people with disabilities, rather than poverty as a risk factor for developing disability.

More data describing the link between disability and poverty are recognised as a pressing global concern [3, 50, 51].

Below, available evidence on disability and poverty are discussed, as well as specific considerations for capturing poverty amongst people with disabilities. In addition, *Chapter 4, Paper 1* presents a systematic review of the association between disability and poverty.

### **1.3.1 Disability considerations across poverty measures**

A key consideration is on how to measure poverty among people with disabilities. The measures used across the conceptual approaches for understanding poverty described previously can be divided into monetary indicators<sup>5</sup> and multidimensional indicators. For example, the capability approach uses primarily multidimensional measures, while the monetary approach uses economic measures. The social exclusion approach may use both, although in practice monetary measures are most common [9]. Participatory approaches may not use quantitative indicators at all, but produce qualitative descriptions of poverty.

This thesis will define monetary/economic measures as including income, material assets and expenditures. Multidimensional measures may include a range of indicators linked to well-being, such as access to education, healthcare, work and social participation.

#### *Monetary measures*

Much of the evidence on disability and poverty has used monetary measures, employing both absolute and relative indicators (in line with monetary and social exclusion approaches to poverty, respectively). Studies have found people with disabilities face high levels of absolute monetary poverty [27, 52, 53], as well as relative poverty compared to people without disabilities in their setting [54, 55]. People with disabilities and their households may be at heightened risk of economic poverty due to lower earnings, often stemming from high levels of unemployment or underemployment amongst people with disabilities [21, 24]. Similarly, other

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<sup>5</sup> Monetary poverty is primarily used throughout the thesis, although economic poverty is also used to describe monetary measures, namely in *Chapter 4, Paper 1*.

household members may forgo time spent on work and other productive activities to provide care or assistance [21].

There are, however, important concerns with assessment of the relationship between disability and monetary poverty [48, 56], and use of common monetary measures may underestimate poverty among people with disabilities for several reasons.

A key concern is that monetary measures are almost always measured at the household-level and generally assume all members have the same consumption needs [21, 52]. Equivalence scales have been used to capture somewhat the differences in consumption needs, as they apply weighting structures that account for differences amongst households in factors such as household size (i.e. to account for economies of scale in larger households) and age composition (i.e. to account for lower consumption needs in children) [57]. While compelling in theory, in practice the use of equivalence scales has been criticised, primarily due to the subjective nature of assigning weight values [58, 59]. Further, standard equivalence scales include age, number of members and sometimes gender, but rarely capture other intra-household characteristics such as disability status. People with disabilities, however, may experience significantly higher consumption needs, as illustrated in the growing body of research on extra costs associated with disability [60-62].

“Extra costs”<sup>6</sup> refers to the additional expenses/consumption needs people with disabilities frequently require in order to participate in society, such as for assistive devices, rehabilitation services and specialist healthcare, added transport or personal assistance [60]. Spending on or access to many disability-specific items is rarely captured in expenditure surveys, even though these goods and services are integral to people with disabilities’ well-being [53, 60]. People with disabilities and their households will bear the greatest burden of these costs in non-inclusive environments (e.g. inaccessible facilities and transportation, lack of coverage of assistive devices and rehabilitation in health insurance policies). Further, failure to meet these costs heightens the risk of isolation and exclusion [3]. People with

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<sup>6</sup> Also called a “conversion handicap” in Sen’s capability approach [17].

disabilities therefore will often require a higher level of wealth to maintain the same standard of living as a person without a disability, who does not have to spend on these items. Consequently, standard poverty lines are likely to underestimate poverty among people with disabilities. For example, extra costs were estimated at 9%, 14% and 19% of household income in Vietnam, Bosnia and Herzegovina, and Cambodia, respectively [53]. Raising the poverty line by the estimated extra costs increased the prevalence of poverty amongst people with disabilities by 3.7-19%. Experts have therefore advocated for adjusting poverty lines for people with disabilities to account for these extra costs [63]. Similarly, relative measures of monetary poverty may underestimate poverty among people with disabilities: due to extra costs, people with disabilities have a higher barrier to social inclusion.

In addition to higher consumption needs, people with disabilities may not receive an equitable share of resources within the household due to factors such as lower decision-making power or discrimination within the household. For example, some studies have found people with disabilities are more likely to be malnourished or less likely to attend school compared to other household members, potentially indicating a lower prioritisation in the division of household resources or other barriers to inclusion [64-66]. Similarly, people with disabilities may not be able to use communal assets such as phones, internet, computers or televisions if these items do not include accessibility features. Consequently, household-level monetary measures of poverty may mask actual well-being amongst people with disabilities [53]

### *Multidimensional measures*

The capability approach has been used increasingly to describe the relationship between disability and poverty [21, 24, 67, 68]. Studies have found that people with disabilities and their households often experience deprivations across common multidimensional indicators, such as lower educational enrolment and attainment [52, 54, 69-71], less sustainable livelihoods [52, 72-75], poorer levels of health and less equitable access to health services [52, 76-78]. For example, people with disabilities faced large gaps in school attendance and attainment, employment and literacy compared to people without disabilities, and experienced high unmet health and rehabilitation needs, in Zimbabwe, Namibia, Malawi and Zambia [47]. Additionally, several studies have used MPIs to assess poverty among people with

disabilities, with all finding strong links between disability and multidimensional poverty [24, 52, 79, 80].

Overall, multidimensional measures represent an advance in understanding poverty amongst people with disabilities [24, 67]. For example, the notion in the capability approach that the possession of a certain amount of resources does not translate neatly into well-being mirrors some of the above critiques of using monetary measures to assess poverty amongst people with disabilities [21, 24]. Notably, the challenges in converting resources to well-being include the extra-costs of disability, as well as other barriers (e.g. availability, discrimination and stigma, physically, socially or financially inaccessible environments). For example, a person with a physical disability may not be able to access schools even if they have the money for fees if associated travel costs are too high, schools are physically inaccessible or teachers refuse to admit students with disabilities.

However, multidimensional poverty measures may still underestimate poverty amongst people with disabilities. Notably, quality is a concern when assessing access to services, employment and education. Although issues of quality are a universal concern, people with disabilities are likely to be disproportionately affected. For example, research has highlighted that children with disabilities attending school may not actually be gaining tangible skills if the school does not have resources in place to support their learning (e.g. instruction in Braille, sign language) [65, 81]. Similarly, markers on access to healthcare (e.g. distance to nearest facility, having health insurance) may be misleading for people with disabilities: for example, people with mobility limitations may struggle to get to facilities if there's no accessible transportation links, or may find they are denied services or receive substandard care due to stigma of disability [3]. Further, available services may not meet the needs of people with disabilities (e.g. if there are no rehabilitation or other specialist services), and so access to healthcare may not translate to better health and well-being.

Additionally, several multidimensional indicators are measured at the household-level, raising similar concerns as with monetary measures on intra-household equity. For example, sanitation facilities and water sources are commonly used in MPIs. However, people with disabilities may not be able to use the same sanitation facility

or water source as others in the household (e.g. due to inaccessible facilities, difficult terrain, discrimination from others when using communal facilities) or in the same way (e.g. hygienically, independently, with privacy and without pain) [82, 83]. Consequently, household access to improved sanitation and clean water may be a less accurate indicator in MPIs for people with disabilities compared to other non-disabled household members.

Finally, certain indicators may not be included in MPIs, but are highly relevant for people with disabilities. Experiences of stigma, discrimination and violence, independent living and autonomy over life choices, as well as access to disability-specific services such as assistive devices, rehabilitation and inclusive education may be particularly important to capture. Participatory approaches to poverty measurement present an important, and underexplored, opportunity for defining important indicators for people with disabilities [45, 84]. For example, Mitra et al. used focus group discussions with people with psychosocial impairments in the United States to select and rank dimensions for an MPI [85]. The study found significant divergence in the selection of dimensions and the ranking of their relative importance between the researcher/expert group and the group of people living with psychosocial impairments, which resulted in differing levels of assessed poverty.

### ***1.3.2 Disability, poverty and the SDGs***

Unlike the MDGs, the SDGs include more of an explicit focus on disability. Disability is referenced directly in several Goals, Targets and Indicators, such as for education (Goal 4), employment and economic growth (Goal 8), inequality (Goal 10) and sustainable cities and communities (Goal 11) [86]. Disability is not mentioned explicitly in poverty-related indicators, with the exception of SDG Target and Indicator 10.2 (social, political and economic inclusion) [44]. However, data disaggregation across all targets and indicators of the SDGs is recommended to identify groups at risk of exclusion so as “to leave no one behind” [50]. Specifically, SDG 17.18, calls for disaggregation of data across all targets and indicators by “income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts” [50].

## **1.4 Conclusion**



There are many different approaches to define and measure poverty, each with its own strengths and weaknesses. Across approaches and measures, however, people with disabilities may be more likely to experience poverty compared to people without disabilities. Additionally, many indicators may underestimate poverty among people with disabilities. More research is needed to describe the relationship between disability and both monetary and multidimensional poverty and to develop appropriate approaches for measuring poverty amongst people with disabilities.

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## **Chapter 2. The role of social protection in alleviating poverty**

## **2.1 The role of social protection in preventing and alleviating poverty**

Social protection programmes are increasingly being implemented by governments in LMICs as a set of strategies for ensuring their citizens are protected from poverty, risk and vulnerability across the life-course [1]. While definitions vary, social protection may be described as “public actions taken in response to levels of vulnerability, risk, and deprivation which are deemed socially unacceptable within a given polity or society” [2].

### ***2.1.1 Approaches to social protection***

The number of social protection programmes in LMICs has expanded rapidly since the 1990s, and with it the proliferation in its conceptualisations [3]. The World Bank’s “Social Risk Management” approach was widely used as a framework for social protection in the wake of the Millennium Development Goals [4]. Under this approach, social protection is viewed as a tool to reduce or prevent poverty and vulnerability, primarily by improving individuals’ or households’ strategies of managing different types of risk (e.g. natural disasters, illness and injury, unemployment) [4, 5]. Risk management strategies are grouped into three categories [5]. Prevention strategies focus on reducing the probability of a risk occurring, for example through improving labour standards or access to routine healthcare. Mitigation strategies seek to decrease the potential impact of a risk if it were to occur, such as through insurance coverage (e.g. health, unemployment) or diversification of assets and sources of income. Finally, coping strategies aim to relieve the impact of a risk once it has occurred, for instance by providing food or cash assistance so that households can meet their basic needs. Social protection under this model is seen as a means to protect a minimum standard of living, as well as help individuals develop stronger livelihoods [4, 5].

However, the social risk management framework has been criticised for focusing too narrowly on economic risks affecting income and assets [4, 6]. Social risks, such as structural inequalities, discrimination and exclusion, are recognised as strong drivers of vulnerability and poverty – particularly chronic poverty – but were deemed not sufficiently included in the social risk management framework [6, 7]. Without attention to these social risks, it was argued that social protection would be unlikely to provide a long-term escape from chronic poverty [7-9].



Consequently, “transformational” social protection was advanced to address social inequalities and exclusion [6]. A core aim of transformational social protection is thus to promote social justice, by empowering and protecting the rights of people living in or vulnerable to poverty and through creating more equitable and inclusive societies [6, 8]. It may involve elements of behaviour change (e.g. sensitisation campaigns to reduce discrimination) or be coupled with legal reforms and advocacy to protect the rights of marginalised groups [6, 7]. Transformational social protection also focuses more explicitly than social risk management on improving the capabilities of people living in poverty, such as through livelihood-enhancing activities (e.g. vocational training, microfinance) and access to social services (e.g. education, healthcare) [7].

The Social Protection Floor approach, led by the International Labour Organization (ILO) and the WHO, with cooperation across United Nations’ agencies, presents a strategy for governments to develop or strengthen social protection systems [10, 11]. At the outset, governments should establish and maintain a “floor” of certain nationally-defined minimum guarantees for all its members. These guarantees should aim to prevent or reduce poverty, vulnerability and social exclusion [11]. They should also at a minimum cover: (a) access to essential goods and services, including healthcare, and (b) basic income security for children, older adults and people of working-age who are unable to earn sufficient income [10, 11]. Once these floors are in place, States should focus on expanding programmes to provide higher levels of protection to as many people as possible [12].

### ***2.1.2 Social protection delivery and instruments***

In LMICs, social protection may be delivered through a range of providers, including governments, non-governmental organisations (NGOs) and international organisations [13]. This thesis, however, will focus on social protection programmes implemented by national governments and grounded in national legislation.

There are variety of instruments that may fall under the banner of social protection [3]. Social assistance and social insurance, however, are considered the core instruments. These instruments may be combined with other programmes, policies or laws to improve access to essential services, codify the rights of vulnerable groups, strengthen individual capabilities, reduce inequalities and combat social exclusion.

### *Social assistance*

Social assistance is the dominant social protection strategy used by governments in LMICs [14]. Social assistance comprises non-contributory transfers in cash or kind, which are typically targeted to people or households currently in or vulnerable to poverty. Examples of social assistance programmes include conditional and unconditional cash transfers, cash/food for work initiatives or food assistance. These programmes provide regular support, and are typically financed through government budgetary allocations [15, 16].

Most social assistance programmes in LMICs have a cash transfer component and may be grouped into three categories: pure income transfers, income transfers combined with asset accumulation or integrated poverty reduction programmes [15, 17]. Pure income transfers are nested in the monetary approach to poverty, which views poverty as resulting from deficits in consumption [15]. They provide a regular source of income with the aim of ensuring recipients can afford a minimum standard of living. This standard may be tied to a minimum food intake, or under more generous schemes, include costs of accessing some essential services [15]. Income transfers combined with asset accumulation meanwhile take a broader understanding of poverty. These programmes view poverty as resulting from insufficient levels of human, physical, financial and other types of assets, or from challenges in using available assets to maximise productivity [15, 18]. Examples of income transfers combined with asset accumulation include many conditional cash transfers, where the cash allotment is tied to recipients investing in their own human capital (e.g. receipt of cash contingent on sending children to school or attending regular health checks).

Finally, integrated poverty reduction programmes addresses social exclusion as a major driver of poverty [17]. These programmes take a multidimensional approach to understanding poverty, as they often combine a range of interventions targeting different forms of deprivation [15]. In addition to a cash transfer, recipients may receive a range of in-kind benefits such as educational scholarships, vocational training or health subsidies, which have the goal of improving social inclusion.

### *Social insurance*

Social insurance may be defined as interventions to mitigate risks over the life-course. For example, health insurance reduces financial hardship from accessing health services in the event of illness or injury, while pensions or unemployment insurance ensure a basic income if an individual is not working. A defining feature of social insurance is that enrolment typically requires contributions from beneficiaries<sup>7</sup> [15]. For example, workers make regular contributions to their pension from their salary, which is may be matched by employers or governments. Similarly, people may purchase health insurance and pay annual premiums or co-payments when accessing services.

Social insurance is often the main component of social protection in high-income countries, although LMICs are beginning to implement these programmes as well [13]. The reach of social insurance, however, is still limited in many LMICs [16]. For example, many programmes offering protections to workers (e.g. pensions, accident/injury/ disability cover) cover only the formal sector [12]. The large proportion of workers in the informal sector in many LMICs are therefore often excluded from these protections [19].

### ***2.1.3 Social protection in the SDGs***

The importance of social protection as a key tool for poverty alleviation is reflected in its inclusion in the SDGs. SDG 1 highlights social protection as a critical strategy for “ending poverty in all its forms” in Target 1.3, which seeks to “implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable” [20]. Further, social protection is referenced directly or indirectly in at least four of the other 17 SDGs (Figure 3). Social protection may also play an important role in achieving many other Goals, such as food security and access to a quality education [21].

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<sup>7</sup> Some programmes waive or reduce contributions for certain groups

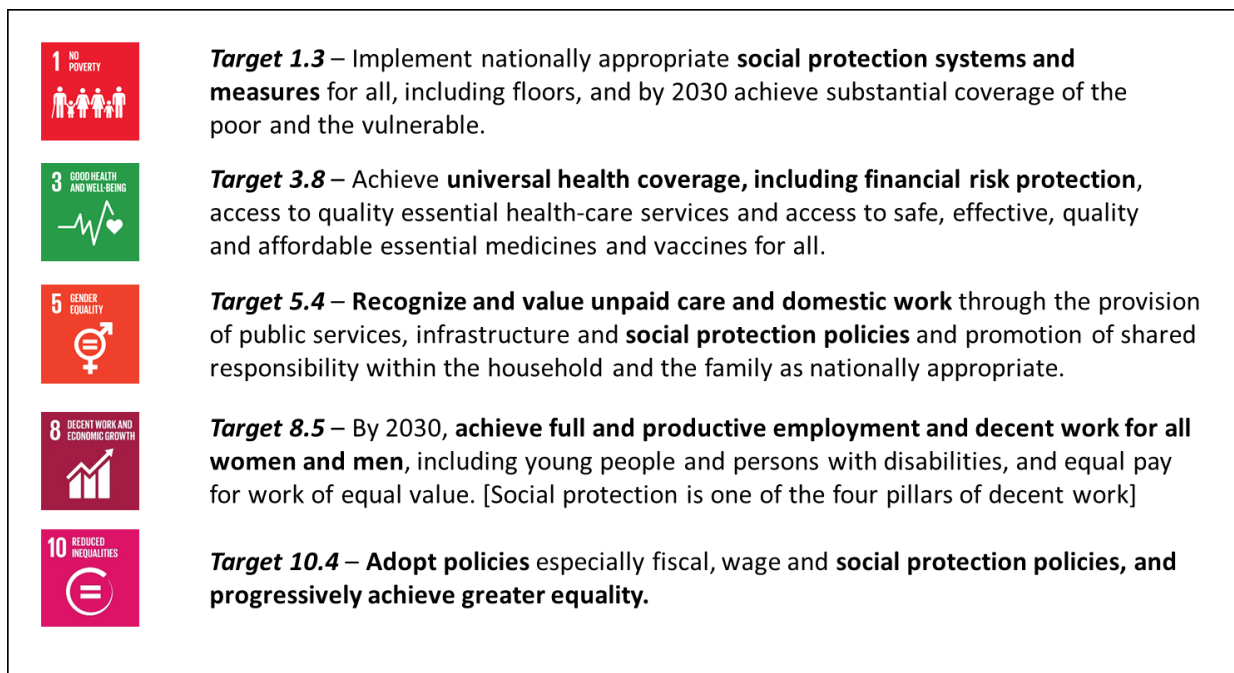


Figure 3 SDGs with direct or indirect reference to social protection (reproduced from International Labour Organization 2017 [16])

## 2.2 Disability and social protection

People with disabilities are often listed as key target groups in national and international social protection frameworks, policies and programmes due to their high levels of poverty and social, economic and cultural exclusion [16, 22]. In addition, the right to inclusion is enshrined in many international treaties, such as the Universal Declaration of Human Rights (Articles 22 and 25) and the UNCRPD (Article 28) [23, 24]. Together, these needs-based and rights-based arguments form the normative basis for inclusion of people with disabilities in social protection plans and programmes.

However, comprehensive strategies for inclusion, beyond simply identifying people with disabilities as a key target group, are often lacking. The absence of clear strategies for promoting disability-inclusive social protection may lower access of people with disabilities to available programmes, or result in reduced effectiveness of programmes in meeting their aims of poverty alleviation, development of stronger livelihoods and social inclusion amongst recipients with disabilities. For example, studies in Tanzania and Peru found low levels of access of people with disabilities to available social protection schemes, despite high levels of need (e.g. poor health,

poverty) [25, 26]. Below, some barriers to the effective inclusion of people with disabilities in the design and delivery of social protection schemes are discussed.

### ***2.2.1 Determining eligibility***

People with disabilities may access social protection through disability-targeted or mainstream schemes. Disability-targeted programmes include disability as an explicit eligibility requirement. Mainstream schemes do not assess disability to determine eligibility, but may implicitly target people with disabilities due to higher levels of poverty or other sources of marginalisation.

Targeting by disability is complex and carries several considerations. A key concern is the classification of people by disability status. The definition of disability used in programmes should be aligned with the UNCRPD (i.e. functioning-based rather than impairment-based, includes consideration of participation restrictions) [27, 28].

However, disability is often defined solely in medical terms (e.g. the presence of a particular health condition or impairment) or is overly restrictive (e.g. disability must limit an individual's capacity to work) [27, 29]. To comply with the UNCRPD, assessments of disability should consider not only the presence of impairment, but also its impact on functioning and participation in a given context [30]. Even when definitions of disability are aligned with the UNCRPD, it can still be difficult to establish whether an individual has a disability. Key challenges include the lack of international agreement on appropriate tools for determining the presence and severity of disability, combined with low administrative capacity to conduct assessments, particularly in rural or remote areas [27, 31]. Consequently, many people with disabilities, particularly with episodic or invisible impairments (e.g. mental health conditions), may be excluded from disability-targeted programmes or face a lengthy – and costly – assessment process [27, 31].

For mainstream schemes, adaptations to eligibility criteria may be needed to ensure that they are inclusive of people with disabilities. Notably, the use of fixed income-based poverty lines to identify all people or households living in poverty fails to take into account the additional disability-related costs experienced [32]. Without consideration of extra costs of disability, the actual level of need amongst people with disabilities will be underestimated and may lead to the exclusion of some people from programmes.

### ***2.2.2 Procedures for applying and accessing benefits***

All steps in the delivery of social protection, from application procedures to the provision of benefits, should be accessible to people with disabilities. Failure to address barriers to access can result in lower programme coverage, and may also reduce programme effectiveness if recipients cannot use benefits as intended once approved.

However, often the infrastructure of application or programme facilities, as well as the buildings of linked services (e.g. healthcare, education, banking) are physically inaccessible, which excludes many people with disabilities, particularly people with mobility limitations [27]. Similarly, getting to facilities may be challenging without accessible and affordable transportation, particularly for people living in remote areas [31, 33, 34].

Further, accessibility of information is a concern, particularly for people with sensory and intellectual impairments [27, 31]. For example, information may not be available in alternative communication formats (e.g. Braille, sign language) or be easily understood [27]. Additionally, outreach to raise awareness of programmes and their application procedures may be limited. Consequently, people with disabilities may not be aware of programmes that they are eligible for, how to apply for them or how to access benefits once enrolled.

Other household members may be instrumental in helping people with disabilities navigate inaccessible application procedures, as well as accessing benefits once enrolled. However, reliance on other household members can limit people with disabilities' autonomy in deciding if and when to apply, as well as in how to use benefits [30].

Finally, discriminatory attitudes by programme staff may dissuade enrolment of people with disabilities in programmes they are eligible for or reduce to their access to benefits once enrolled [31].

### ***2.2.3 Relevance of benefit packages***

Under a transformational approach, social protection benefits should ensure people with disabilities enjoy an adequate standard of living and exercise their social, economic and cultural rights on an equal basis as others [27]. To do so, benefits

should be aligned with the needs of people with disabilities and be relevant for the contexts in which they live.

Addressing disability-related costs has been identified as an important role for social protection [28, 31, 35]. These costs may be covered through in-kind or cash transfers. Cash transfers are generally preferred as they allow the recipient greater choice in selecting relevant goods and services, which will vary between individuals and across contexts [36]. However, the value of cash transfers often is insufficient to cover many disability-related costs [35]. For example, mainstream cash transfers given to people living in poverty often provide a fixed benefit level for all recipients. Consequently, recipients with disabilities must cover both basic needs and disability-related expenses from the same allotment. Another concern is that in-kind benefits (e.g. subsidised transportation, scholarships, healthcare) may not be tailored to meet the needs of people with disabilities [35]. For example, accessible transportation may not be available, or health insurance may not cover rehabilitation services and assistive devices required [26].

Other research has highlighted that programmes may create disincentives for social participation [32, 37]. For example, some disability-targeted programmes stipulate that recipients must not be working or bundle income support to reduce poverty with benefits covering disability-related costs (e.g. healthcare, assistive devices, personal assistance) [27, 37]. These requirements create disincentives to participating in work and developing more stable livelihoods, as the recipient must choose between working or earning a higher income, and maintaining a steady source of support [27, 35, 38].

## **2.3 Conclusion**

Social protection is an important tool for alleviating poverty, improving livelihoods and reducing inequalities and social exclusion. People with disabilities are often listed as a key target group of social protection, due to high levels of poverty and social exclusion. The right of people with disabilities to social protection is also enshrined in international and national policies and legislation. However, programmes are unlikely to reach and benefit people with disabilities unless comprehensive strategies are adopted to address barriers to access and ensure benefits meet the needs of people with disabilities. More research is essential to

explore whether people with disabilities are accessing and benefiting from available social protection schemes in LMICs.

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## **Chapter 3. Study rationale, aim and objectives**

### **3.1 Study rationale**

Social protection programmes are increasingly being implemented by governments in LMICs and many either explicitly or implicitly targeted people with disabilities as key beneficiaries [1]. For example, according to the International Labour Organization, 170 national governments (91% of countries globally) have implemented disability-targeted cash transfers [2]. Similarly, a review of 52 countries in Africa and Asia & the Pacific identified 215 social protection schemes that referenced disability in their design [1]. However, the 2015 annual report by the United Nations Special Rapporteur on the rights of persons with disabilities highlighted that there is a lack of robust research on disability and social protection, which is critical for informing evidence-based social protection policy and programming [3]. Consequently, the body of work produced in this thesis seeks to contribute towards improving the evidence base on the challenges and opportunities for disability-inclusion in social protection.

First, it is important to understand the need for social protection amongst people with disabilities in order to advocate for and design relevant social protection programmes. This thesis assesses need for social protection by exploring the link between disability and different forms of poverty. Other studies have noted that this relationship is under-researched, even though the international development community increasingly recognises that many people with disabilities face a heightened risk of poverty and vulnerability [4].

Second, measuring access to available programmes is needed to understand if they are adequately reaching people with disabilities. In this regard, very few studies have been conducted that evaluate participation of people with disabilities in social protection. Some studies suggests access falls far below need [5, 6], although most available data are modelled estimates, focus only disability-targeted programmes or do not assess equity in access compared to people without disabilities [2].

Finally, it is essential to assess if social protection is adequately meeting the needs of recipients with disabilities. Currently, there is a dearth of knowledge exploring whether receipt of social protection is sufficient to protect against poverty, as well as meet its other goals of developing stronger livelihoods, reducing inequalities and combatting social exclusion. It is critical to determine whether social protection is

fulfilling its intended aims amongst people with disabilities given the emphasis on social protection in the SDGs and other initiatives as a core tool for poverty alleviation and social inclusion.

### 3.2 Aim

The overall aim of this thesis is to explore need for and access to social protection amongst people with disabilities, and evaluate the extent to which existing programmes are adequate in meeting the needs of people with disabilities.

### 3.3 Objectives

1. To systematically review the literature on the relationship between disability and economic poverty in LMICs. *(Chapter 4, Paper 1)*
2. To systematically review the literature on access to and impact of social protection amongst people with disabilities in LMICs. *(Chapter 5, Paper 2)*
3. To compare economic and multidimensional poverty among people with and without disabilities in Cam Le, Vietnam and Tanahun, Nepal. *(Chapter 6, Paper 3)*
4. To evaluate access of people with disabilities to existing social protection programmes in Cam Le, Vietnam and Tanahun, Nepal. *(Chapter 7, Paper 4 and 5)*
5. To explore the adequacy of available social protection programmes in protecting against poverty amongst recipients with disabilities in Cam Le, Vietnam and Tanahun, Nepal. *(Chapter 8)*

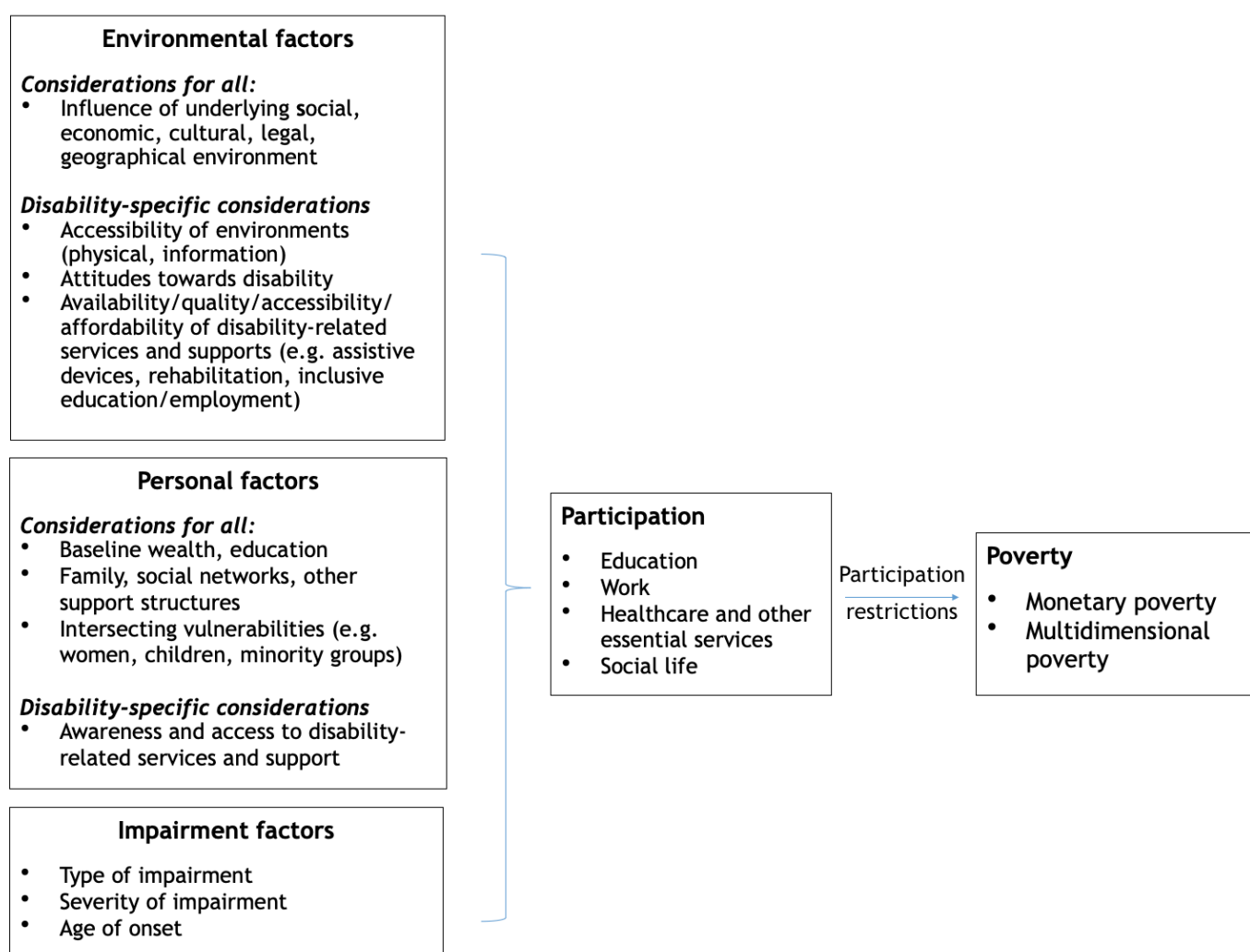
### 3.4 Key research questions and hypotheses

This research will ask the following research questions to test the embedded hypotheses.

- (1) Are people with disabilities more likely to be living in economic and multidimensional poverty compared to people without disabilities? How does the risk of poverty differ amongst people disabilities?*

**Hypothesis:** People with disabilities are more likely to be living in both economic and multidimensional poverty compared to people without disabilities. Amongst people with disabilities, risk of poverty will differ depending on the extent to which the interaction between impairment, environment and personal factors lead to participation restrictions.

The above hypothesis is grounded in the ICF framework of disability [7] and approaches to conceptualising poverty set out in *Chapter 1* (monetary, capability and social exclusion approaches) [10, 11]. Figure 1 presents an overarching conceptual framework embedded in the ICF that can demonstrate ways in which people with disabilities' risk of economic and multidimensional poverty is linked to the interaction between participation restrictions, impairment/functional limitations as well as personal and environmental factors. This framework will be tested through the research outlined in this PhD.



**Figure 1. Framework on disability and poverty**

In Figure 1, participation restrictions are the ultimate cause of both multidimensional and economic poverty amongst people with and without disabilities. Participation restrictions may lead directly or indirectly to economic poverty (e.g. lack of income

from unemployment, lack of education leading to fewer job opportunities) or may themselves be considered indicators of multidimensional poverty (e.g. exclusion from education, inadequate access to key services). Participation restrictions and resulting poverty can be linked to personal and environmental factors, some of which may be experienced by both people with and without disabilities. However, people with disabilities are expected to face an increased risk of economic and multidimensional poverty as they often must contend with additional barriers to participation from the interaction of impairment/functioning with unique environmental and personal factors.

Under the monetary approach, economic poverty is caused by participation restrictions in areas that lead to a loss of income and other financial resources (e.g. exclusion from decent work, other profit-generating activities). Participation in economically-productive activities for both people with and without disabilities will be influenced by environmental factors (e.g. availability of jobs, their standard remuneration rates in a certain area, costs of goods and services) and personal factors (e.g. individual's skill set, social connections that can be used to access prospective employers). However, studies have found people with disabilities are particularly likely to be excluded from participating in work and other economically productive activities [7], which may be explained by additional impairment/functioning, personal and environmental factors. For example, an impairment can restrict the type of activities that a person is able to perform, which depending on age of onset (e.g. working years vs older age), severity and access to assistive technology, can influence the type of jobs a person can perform. Even if a person is able to perform all activities necessary for a job, they may still be excluded from work due to other environmental factors such as stigma of disability from employers or potential customers or the lack of disability-inclusive planning in linked services and facilities (e.g. inaccessible transportation, workplace buildings).

Figure 1 is also in line with the capability approach, in which participation restrictions can be equated with a failure to achieve desired functionings across a range of life areas that the individual and society deems to be important (e.g. being employed, going to school) [8]. Achieving these functionings will depend on an individual's set of capabilities, which are influenced by their personal and environmental characteristics - and for people with disabilities, how these factors interact with their

impairment. People with disabilities may therefore face additional hurdles to achieving desired functionings compared to people without disabilities. For example, people with disabilities may face extra costs to participation, if they have to pay for items and services needed to improve functioning and navigate environments that are inaccessible to them.

Additionally, the social exclusion approach emphasises the importance of environmental factors as a cause of participation restrictions and poverty. The social exclusion approach explains how environmental factors such as stigma and discrimination of disability and persistent structural inequalities (e.g. inaccessible information, physical environments) can lead to persistent participation restrictions - and thus poverty - amongst people with disabilities compared to people without disabilities.

Finally, Figure 1 describes not only why people with disabilities face an increased risk of economic and multidimensional poverty compared to people without disabilities, but also why risk of disability varies amongst people with disabilities. The risk of poverty will differ amongst people by impairment type, setting and their personal characteristics. For example, two people with disabilities with a physical impairment may differ in their ability to work and earn an income based on personal characteristics such as their access to an assistive device and their skill set as well as environmental factors such as the types of jobs available in the area (e.g. office-based vs agricultural), attitudes towards disability and the physical accessibility of the surrounding environment.

*(2) What proportion of people with disabilities are enrolled in social protection schemes? How does participation in social protection differ amongst people with disabilities and in comparison to people without disabilities?*

**Hypothesis:** Enrolment in social protection will be below need. Certain groups of people with disabilities will be more likely to access social protection, depending on: (a) the availability of programmes and their eligibility criteria in a given context; and (b) how impairment, personal and environmental factors impact interest in, awareness and access to programmes that people with disabilities are eligible for.



It is anticipated that many people with disabilities will not be accessing social protection programmes across LMICs, including the two case study districts in Nepal and Vietnam, even if they are facing economic or multidimensional poverty. In some cases, people with disabilities will not access programmes due to how eligibility criteria are defined. For instance, some people with disabilities will not be able to enrol in disability-targeted programmes due to how programmes' conceptualise and assess disability. Similarly, means-tested programmes may not recognise economic poverty amongst people with disabilities due to the failure to account for additional costs of disability.

Additionally, people with disabilities may not access social protection programmes even if they are eligible for them. People with disabilities may not be aware of available programmes, how to apply for them, or need support to complete applications. As with the risk of experiencing poverty, the extent to which people with disabilities face these barriers and their ability to overcome them can depend on the interaction of impairment, personal and environmental factors. For example, a person with a visual impairment may not apply for social protection if information about the programme and application materials are not available in an accessible format, or may not think they are eligible due to social norms in their setting about what constitutes disability (e.g. functional loss from ageing not seen as disability).

*(3) Are existing social protection schemes adequate to protect people with disabilities from economic and multidimensional poverty?*

**Hypothesis:** Most social protection programmes will be inadequate to fully protect people with disabilities from economic and multidimensional poverty. Gaps are likely to persist, particularly for multidimensional poverty.

The ability of social protection to protect against economic and multidimensional poverty will depend on the content of programmes and how, if at all, they are able to alter the relationship between disability and poverty outlined in Figure 1.

For example, cash transfers and insurance can ensure households' are able to maintain a basic income above the monetary poverty line, if they are of sufficient value. Further, social protection may target some of the drivers of participation

restrictions and poverty. For instance, social assistance or insurance can help overcome financial barriers to participation in key activities (e.g. waiving school fees to enable participation in education, coverage of user fees to improve access to needed health services). Some programmes also incentivise or require beneficiaries to partake in certain activities by tying receipt of benefits to participation (e.g. conditional cash transfers linked to participation in school and various health initiatives).

However, it is expected that most social protection programmes on their own will be insufficient to fully protect people with disabilities from poverty, particularly multidimensional poverty. A key concern is whether social protection programmes can adequately target environmental drivers of poverty amongst people with disabilities. For example, a person with a physical impairment may be able to access rehabilitation and a wheelchair through social assistance or insurance programmes, which may decrease the severity of their impairment and improve their mobility. They may still face significant participation restrictions in areas such as work or school if, for instance, office, school and transportation facilities are physically inaccessible and employers and educators hold discriminatory attitudes towards people with disabilities. Integrated poverty reduction programmes that focus on impairment, environmental and personal factors that drive the relationship between disability and poverty are most likely to be successful at reducing both economic and multidimensional poverty.

### **3.5 Implementation of the research**

Lena Morgon Banks was the lead researcher on the two systematic reviews. Her key activities for both papers included: formulation of review protocol, including the development of search terms and inclusion/exclusion criteria; database searching and title/abstract/full-text review of retrieved records; quality assessment of included articles; data extraction and analysis; and write-up for publication. Dual review of included studies and their quality assessment was conducted by co-authors (Sarah Polack, Hannah Kuper and Rachel Mearkle) and all co-authors were involved in the conceptualisation of the research and reviewed article drafts.

For the case studies in Vietnam and Nepal, the overall study protocol and methods were developed by Lena Morgon Banks, Professor Hannah Kuper, Dr. Karl Blanchet and Matthew Walsham. Morgon Banks was the lead researcher on all quantitative data collection and analysis across the Vietnam and Nepal case studies. For both case studies, her key responsibilities included: collaboration with in-country implementing partners (Hanoi University of Public Health (HUPH) in Vietnam and the Valley Research Group (VaRG) in Nepal); development of quantitative survey instruments, including electronic entry forms; training of data collectors and supervision of data collection; data cleaning and analysis; and write-up of all findings for publication.

Each case study also included a policy analysis and qualitative research, which are included in Papers 4 & 5. These components were led by Matthew Walsham and team members in Vietnam (Dr Hoang Van Minh, Dr Vu Duy Kien, Tran Thu Ngan, Vu Quynh Mai, Tran Bich Phuong, Nguyen Bao Ngoc, Dr Doan Thi Thuy Duong) and Nepal (Saurav Neupane, Shailes Neupane, Dr Yogendra Pradhananga, Mahesh Maharjan). This group was responsible for developing study instruments (e.g. semi-structured interview guides), data collection (e.g. reviewing policy documents, conducting all interviews), data analysis and preliminary write-up. Morgon Banks reviewed preliminary findings and then finalised and wrote-up themes as they are presented in the included research papers.

All research papers included as part of this thesis were written by Morgon Banks and then reviewed by co-authors.

Professor Hannah Kuper and Dr Karl Blanchet provided supervision and mentorship throughout the implementation of this research.

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## SECTION B. AVAILABLE EVIDENCE FROM ACROSS LOW- AND MIDDLE- INCOME COUNTRIES ON DISABILITY, POVERTY AND SOCIAL PROTECTION



*Photo: Qualitative interview with a young girl with a hearing impairment*

### Overview

Section B presents two systematic reviews, which collate and evaluate available evidence on need for, access to and impact of social protection amongst people with disabilities in LMICs. *Chapter 4, Paper 1* explores the relationship between disability and economic poverty in LMICs, while *Chapter 5, Paper 2* assesses access to and impact of social protection amongst people with disabilities in LMICs.

## ***Chapter 4. Economic poverty and disability in low- and middle-income countries: a systematic review***

### **Preamble**

Preventing and alleviating poverty – particularly monetary poverty – is highlighted as a key aim of social protection in national and international policies and frameworks [1, 2]. Many social protection programmes have targeted people with disabilities on the assumption that they are more likely to be living in poverty or face vulnerabilities that heighten their risk of becoming poor (e.g. exclusion from employment, education) [3]. Although there has been broad agreement on a link between disability and poverty, robust empirical evidence substantiating and describing this relationship has been less lacking [4].

This chapter presents the findings from a systematic review of the relationship between disability and economic poverty across LMICs. Economic poverty<sup>8</sup> was defined as income, material assets or expenditures; more multidimensional measures of wealth or socioeconomic status were included as long as they were constructed with at least one economic indicator. While acknowledging that poverty can take other forms beyond a deprivation in financial resources [5], economic measures are still the most frequently used in international comparisons and do provide important information about an individual or household's well-being. Additionally, the dominance of cash transfers in LMICs frames poverty as a deficit in financial resources, namely income [2, 6].

The review compiles and evaluates evidence from 150 studies undertaken in LMICs. Included studies cover a range of countries, utilise different measures of disability and economic poverty and survey people with disabilities across impairment types, age groups and settings. Both relative and absolute measures of economic poverty are included in this review. Comparisons are always between people with and without disabilities, which captures economic exclusion. Although not explored systematically, indicators on employment were also collected from included studies

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<sup>8</sup> The rest of this thesis uses the terminology “monetary poverty”, which is used synonymously with economic poverty here.

to explore possible mechanisms explaining the link between disability and economic poverty.

This research paper was published in the journal *PLoS One* after peer review in December 2017. Web appendices can be found in Appendix 6 of this document.

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## Paper 1: Poverty and disability in LMICs

### RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

#### SECTION A – Student Details

Student	Morgon Banks
Principal Supervisor	Prof Hannah Kuper
Thesis Title	Investigating disability-inclusion in social protection programmes in low and middle income countries, with case studies from Vietnam and Nepal

*If the Research Paper has previously been published please complete Section B, if not please move to Section C*

#### SECTION B – Paper already published

Where was the work published?	PLoS One		
When was the work published?	December 2017		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

*\*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.*

#### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

#### SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Led on conceptualisation (development of methods, e.g. search strategy, inclusion/exclusion criteria), data collection, analysis. Wrote the original draft, which was reviewed by the other co-authors. Responsible for submitting to the journal and incorporating feedback from the journal's
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	peer review.
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Student Signature: \_\_\_\_\_

Date: Mar 12, 2019

Supervisor Signature: \_\_\_\_\_

Date: 26/3/19



# **Poverty and disability in low- and middle-income countries: A systematic review**

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## Abstract

**Introduction:** Disability and poverty are believed to operate in a cycle, with each reinforcing the other. While agreement on the existence of a link is strong, robust empirical evidence substantiating and describing this potential association is lacking. Consequently, a systematic review was undertaken to explore the relationship between disability and economic poverty, with a focus on the situation in low and middle income countries (LMICs).

**Methods:** Ten electronic databases were searched to retrieve studies of any epidemiological design, published between 1990-March 2016 with data comparing the level of poverty between people with and without disabilities in LMICs (World Bank classifications). Poverty was defined using economic measures (e.g. assets, income), while disability included both broad assessments (e.g. self-reported functional or activity limitations) and specific impairments/disorders. Data extracted included: measures of association between disability and poverty, population characteristics and study characteristics. Proportions of studies finding positive, negative, null or mixed associations between poverty and disability were then disaggregated by population and study characteristics.

**Results:** From the 15,500 records retrieved and screened, 150 studies were included in the final sample. Almost half of included studies were conducted in China, India or Brazil (n=70, 47%). Most studies were cross-sectional in design (n=124, 83%), focussed on specific impairment types (n=115, 77%) and used income as the measure for economic poverty (n=82, 55%). 122 studies (81%) found evidence of a positive association between disability and a poverty marker. This relationship persisted when results were disaggregated by gender, measure of poverty used and impairment types. By country income group at the time of data collection, the proportion of country-level analyses with a positive association increased with the rising income level, with 59% of low-income, 67% of lower-middle and 72% of upper-middle income countries finding a positive relationship. By age group, the proportion of studies reporting a positive association between disability and poverty was lowest for older adults and highest for working-age adults (69% vs. 86%).

**Conclusions:** There is strong evidence for a link between disability and poverty in LMICs and an urgent need for further research and programmatic/policy action to break the cycle.

## Introduction

Globally, it is estimated that 15% of the global population – representing 1 billion people – is living with a disability [1].

Poverty and disability are believed to operate in a cycle, with the one reinforcing the other. In low- and middle-income countries (LMICs) in particular, conditions associated with poverty, such as lack of access to healthcare, inadequate water and sanitation, malnutrition and poor living conditions, increase the risk of disability [2, 3]. Even in the absence of absolute poverty, social inequalities and relative poverty can lead to stress and social exclusion, which can worsen both mental and physical health and functioning [4]. On the other side, disability can lead to exclusion from work, education and healthcare, as well as high healthcare and other expenses, which can cause or exacerbate poverty [5-8].

While there is broad agreement of a link between disability and poverty, the empirical evidence for this association is less clear. Typically, a small set of statistics are routinely cited – for example, that people with disabilities are twice as likely as people without disabilities to be living in poverty [3, 9]. However, despite their widespread citation, upon tracing to the original source, many such figures were found to be based on decidedly weak evidence [9].

A key focus of the development agenda, including the 2030 Sustainable Development Goals (SDGs), is the alleviation of poverty in all its forms [10]. The failure to include disability issues in the predecessor Millennium Development Goals has been recognised as leading to the exclusion of people with disabilities from its benefits, potentially widening inequalities between people with and without disabilities [11]. Consequently, the SDGs have striven to ensure “no one is left

behind” by promoting a stronger focus on disability, including in the call to disaggregate data monitoring progress by disability status.

While the interplay of poverty and disability is increasingly identified as a major limitation to growth and development, the lack of robust empirical evidence to inform policy and programmatic decisions may impede effective action. Efforts to provide a more cohesive understanding of the association between disability and poverty have highlighted a need for further research in this field to both substantiate and describe linkages. A critical review on poverty, health and disability in LMICs conducted in 2011, concludes that while some studies do show strong links, the evidence base is relatively limited and the relationship between poverty, disability and health may be more complex than previously assumed. As acknowledged by the authors, however, this was a non-systematic review which identified a relatively small collection of studies [9]. Similarly, a review on childhood disability and home socio-economic circumstances in LMICs found that quantitative evidence of an association was inconclusive and inconsistent [12]. Both of these reviews used only general terms for disability in their search strategies (e.g. “disability”, “handicap”) and did not include terms for specific disability types (e.g. vision impairment, intellectual impairments) and thus may have potentially excluded many relevant studies.

While poverty can take many forms, economic measures (e.g. income, assets, consumption) are the most frequently used in international comparisons and provide valuable information about an individual or household’s well-being, relative or absolute deprivation and ability to meet basic needs [9]. We have thus undertaken a systematic literature review of empirical studies that compare the level of economic poverty between people with and without disabilities in LMICs. By using systematic methods and extensive search strategies, this review aims to provide a more comprehensive analysis which will build on the existing efforts.

## **Methods**

This systematic review explores the relationship between disability and poverty, including whether characteristics such as impairment type, gender or study location modify this relationship. The review was conducted in line with PRISMA guidelines (S1 Table for PRISMA Checklist [Appendix 8]) [13].

## **Search strategy**

The following ten electronic databases were searched in March 2016 for studies assessing the relationship between disability and economic poverty: EMBASE, PubMed, MEDLINE, Global Health, Web of Knowledge, Academic Search Complete, FRANCIS, ERIC, Social Policy & Practice and EconLit. Additionally, references of relevant review articles were checked to identify additional potential studies.

Comprehensive search terms for poverty, disability and low and middle income countries (LMICs) were identified through MeSH/Emtree as well as from those used for systematic reviews on similar topics (see S1 File for sample search string [Appendix 6]) [14, 15]. The search was limited to English-language titles and articles published between 1990- March 2016.

## **Inclusion/exclusion criteria**

Since the purpose of this review focused on the published evidence for a relationship between poverty and disability in LMICs, only papers involving all three of these topics were included. Papers exploring both directions of association between poverty and disability, as well as those in which the directionality was not evident, were included in the final sample. We included studies that assessed disability broadly (e.g. through self-reported functional or activity limitations) as well as studies that focussed on specific impairments or disorders (vision, hearing and physical impairments, intellectual disability and mental disorders) measured using standardised tools or clinical measures. Poverty was restricted to economic measures, namely income, expenditures, assets and/or socioeconomic status (SES). SES measures could include a range of indicators as part of their composition (e.g. housing characteristics, access to services, education level); however to be eligible for inclusion, measures of SES had to include at least one economic indicator (income, expenditures, or assets) [16]. Poverty could be defined as absolute or relative.

Studies with an epidemiological design were eligible for inclusion. Only studies with comparison groups (i.e. to allow comparison of people with disabilities to people without disabilities) were included. Qualitative studies, review articles and case reports were excluded.

## Study selection

Articles were screened by one reviewer (LMB) first by titles, then abstract and then finally by full paper to determine eligibility. Ten percent of the abstracts were dually reviewed by a second reviewer (SP or HK) to check for agreement.

The full-text of all eligible studies were assessed against quality criteria [15] independently by two reviewers (LMB with either HK or SP; see table 1 for the quality assessment criteria). Differences between the reviewers were discussed and a consensus was reached on all papers. We excluded studies deemed to have a high risk of bias.

**Table 1: Quality assessment criteria and ratings.**

<b><u>Assessment criteria by study design</u></b>	
<i>All study designs</i>	
<ul style="list-style-type: none"><li>• Study design, sampling method is appropriate to the study question</li><li>• Adequate sample size, e.g. sample size calculations undertaken</li><li>• Response rate reported and acceptable (&gt;70%)</li><li>• Disability/impairment measure is clearly defined and reliable</li><li>• Economic measure is clearly defined and reliable</li><li>• Potential confounders taken into account in analysis</li><li>• Confidence intervals are presented</li></ul>	
<i>Case control (additional criteria)</i>	
<ul style="list-style-type: none"><li>• Cases and controls are comparable</li><li>• Cases and controls are clearly defined</li></ul>	
<i>Cohort (additional criteria)</i>	
<ul style="list-style-type: none"><li>• Groups being studied are comparable at baseline</li><li>• Losses to follow up are presented and acceptable</li></ul>	
<b><u>Risk of bias:</u></b>	
Low	All or almost of the above criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study
Medium	Some of the above criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study
High	Few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion. These studies were excluded from the final sample

*Adapted from Lund et al, 2010 [15]*

## **Data extraction and analysis**

Data extracted from the final selection of articles included:

- Study Design
- Method of assessment (poverty and disability),
- Setting (country, site of recruitment),
- Population characteristics (disability type, gender and age)
- Primary research outcome (measure of association between disability and poverty: univariate and multivariate).

In addition, although terms for employment were not included in the search strategy, the association between disability and employment status was recorded as a secondary outcome measure for the studies that conducted these analyses. All extracted values were checked by the second reviewer (SP or HK) to ensure accuracy.

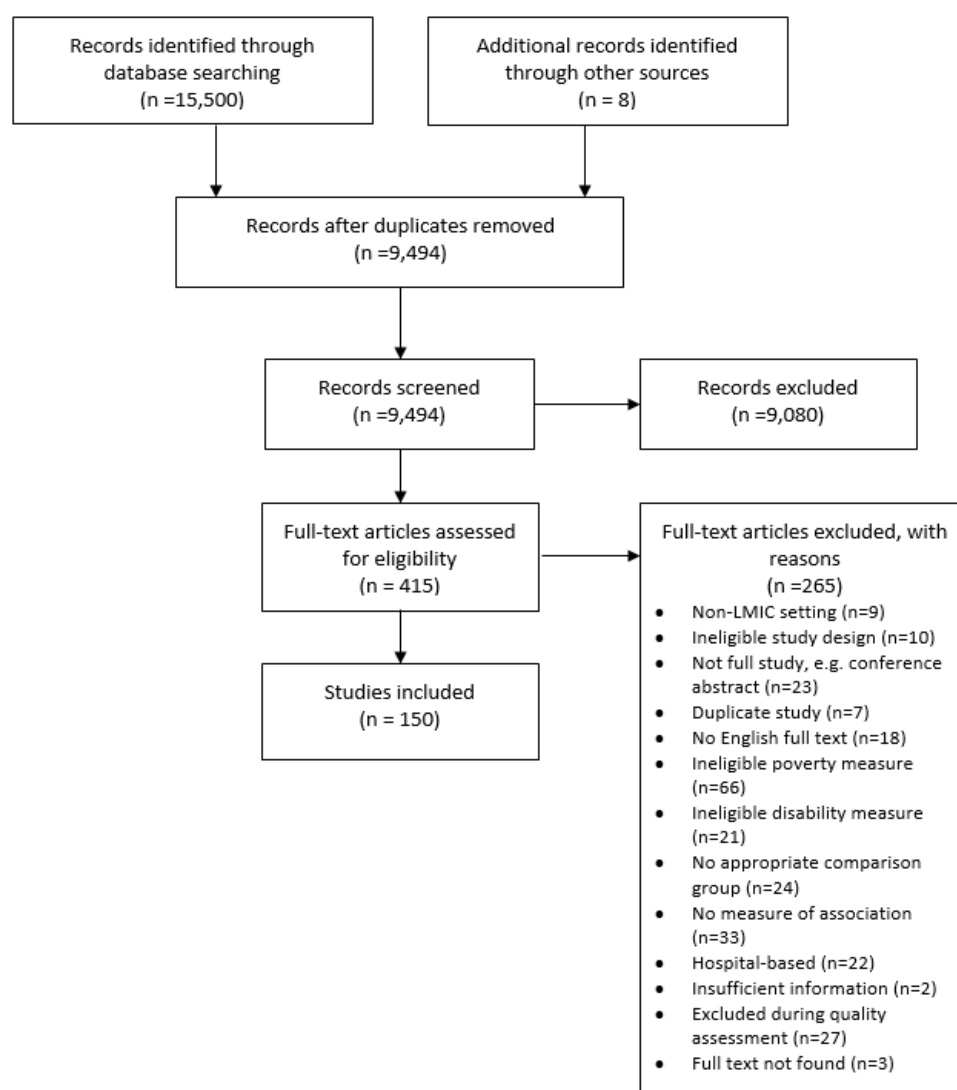
In classifying study outcomes, an association was classified as 'positive' if either: a) the disability measured was significantly more common among poorer compared to wealthier economic groups or b) people with disabilities were significantly poorer compared to people without disabilities. Reverse associations (e.g. disability was significantly less common among poorer compared to wealthier economic groups) were categorised as 'negative'. All classifications of association were made based on statistical significance, after adjusting for confounding (for studies employing multivariate analyses). Consequently, if findings did not achieve statistical significance after adjustment for at least one measure of the relationship between disability and poverty, they were labelled as having 'null association'. If studies presented more than one measurement of association, it was classified as positive or negative if at least one association was statistically significant and the others were null; if both positive and negative statistically significant associations were found, the study was classified as 'mixed'.

Proportions of studies finding positive, negative, null or mixed associations were then disaggregated by study characteristics, including disability/impairment type, age group of the sample (children, adults, older adults) and poverty indicator used, to

explore whether such characteristics modify any relationship between disability and poverty.

## Results

The database search generated a total of 15,500 records (9,494 after duplicates removed and years restricted), of which 7,534 and 1,546 records were excluded in the title and abstract screening, respectively. The full-texts of 415 articles were then assessed for inclusion. Of these 265 were deemed ineligible and 3 untraceable. A further 27 articles were excluded during the quality assessment. An additional 8 eligible articles were identified from reference lists of included articles and other reviews, providing a final sample of 150 studies (Fig 1)(see S2 File for included study citations [Appendix 6]).



**Fig 1: Flowchart of search results**



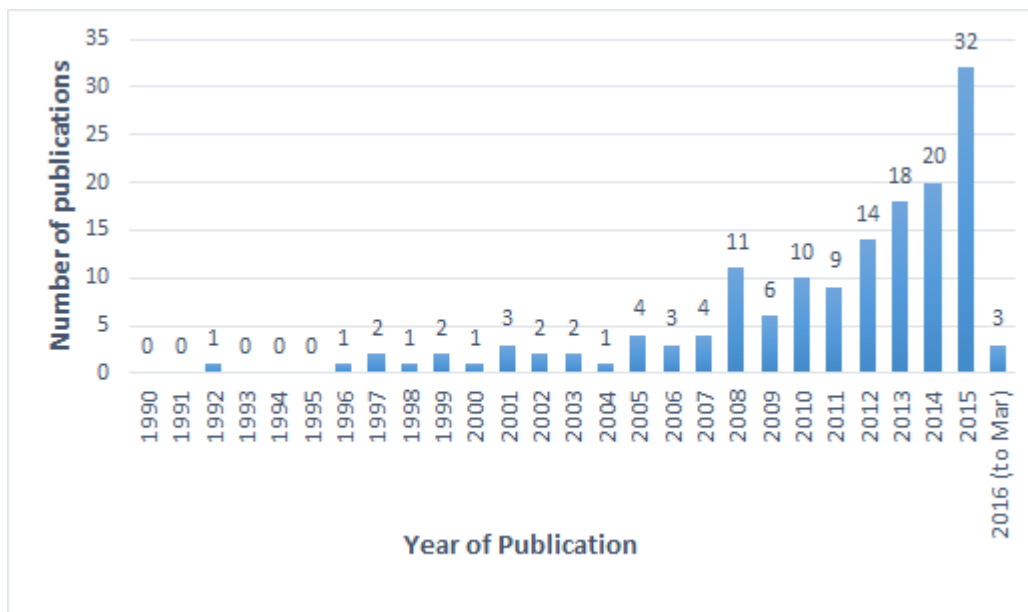
## Overview of study characteristics

Table 2 shows a breakdown of study characteristics. The majority of the included studies (almost 90%) were published from the mid-2000s onwards (Fig 2: Number of included studies by year of publication). Geographically, the largest number of studies were conducted in East Asia & the Pacific (n=39, 27%; China=29) followed by Latin America & the Caribbean (n=31, 19%; Brazil n=26), South Asia (n=26, 20%; India n=17), Sub-Saharan Africa (n=22, 15%), Middle East/North Africa (n=11, 8%) and Europe/Central Asia (n=4, 3%). Of note, almost half of included studies were conducted in China, India or Brazil (n=70, 48%). In addition, 16 studies were multi-regional. By country income group at time of data collection [17], study settings were relatively evenly split (low-income, n=38; lower-middle, n=42; upper-middle, n=48). (See S2 Table for summarised extraction table [Appendix 6]).

**Table 2. Characteristics of included studies<sup>9</sup>.**

		<b>Number<sup>a</sup></b>	<b>%</b>
<b>Region</b>	East Asia/Pacific	40	27
	Latin America/Caribbean	31	21
	South Asia	26	17
	Sub-Saharan Africa	22	15
	Middle East/North Africa	11	7
	Europe/Central Asia	4	3
	Multi-region	16	11
<b>Disability type<sup>b</sup></b>	Visual impairment	12	8
	Hearing impairment	2	1
	Physical impairment	12	8
	Intellectual/cognitive impairment	23	15
	Mental disorders	73	49
	Mixed impairments/functional limitations	37	25
<b>Disability measure</b>	Impairment	114	76
	Activity/functional limitations	32	21
	Mixed	4	3
<b>Location</b>	Rural	17	11
	Urban	50	33
	Both	83	55
<b>Study design</b>	Cross-sectional	124	83
	Case-control	11	7
	Cohort	13	9
	Other	2	1
<b>Setting</b>	Community-based	133	89
	Hospital/clinic-based	6	4
	Schools	9	6
	Other	2	1
<b>Sample size<sup>a</sup></b>	Smallest	85	
	First quartile (25 <sup>th</sup> percentile)	1,188	
	Median (50 <sup>th</sup> percentile)	3,591	
	Third quartile (75 <sup>th</sup> percentile)	10,667	
	Largest	2,600,000	
<b>Age group<sup>c</sup></b>	Children	23	15
	Adults	41	27
	Older adults	48	33
	Mixed ages	38	25
<b>Income group</b>	Low	38	25
	Lower-middle	49	33
	Upper-middle	45	30
	Mix	18	12
<b>Poverty indicator<sup>b</sup></b>	Income	82	55
	SES	36	24
	Assets	30	20
	PCE	10	7
	Other	2	1
<b>Risk of bias</b>	Low	81	54
	Medium	69	46

<sup>9</sup> Tables 2 & 3 as presented here are from the following correction issues on from the original published version: Banks, Lena Morgon, Hannah Kuper, and Sarah Polack. "Correction: Poverty and disability in low-and middle-income countries: A systematic review." *PloS one* 13.9 (2018): e0204881.



**Fig 2: Number of included studies by year of publication**

Concerning study design characteristics, the vast majority ( $n=124$ , 83%) were cross-sectional studies. The remainder were comprised of 11 case-control, 13 cohort studies, one pre-post and one ecological study. The majority of studies recruited participants from the general population ( $n=133$ , 89%), while hospitals/clinics ( $n=6$ ), and schools ( $n=9$ ) were utilized for the rest. In terms of the study population age groups, 48 studies focused on older adults only (33%), 41 included working age adults only (27%), 23 included children/adolescents only (15%) and 37 included participants across age categories (25%).

The majority of studies ( $n=114$ , 77%) focussed on specific impairment types (e.g. vision or hearing impairment) and most used clinical examinations or standardised, objective assessment tools. However, some studies ( $n=33$ , 23%) used indicators such as self-reported activity or functional limitations that are more in line with the World Health Organisation International Classification of Functioning, Disability and Health model of disability [18]. Mental disorders ( $n=73$ , 49%) were the most frequently assessed disability type, followed by intellectual/cognitive impairments ( $n=23$ , 15%), functional limitations/mixed impairment types ( $n=37$ , 25%), sensory impairments ( $n=14$ , 9%) and physical impairments ( $n=12$ , 8%).

Income was the most frequently measured indicator for economic poverty (n=82, 55%). Most studies reported total or per capita family/household income, while a small number reported individual or household head income, satisfaction with income and change in income over the life course. SES was the second most common economic measure (n=36, 24%), followed by asset ownership (n=30, 20%). The majority of SES indices were based on ownership of assets and household characteristics while some included other more multidimensional facets such as education, occupation, income, sanitation facilities and use of services. A smaller number of studies collected data on per capita expenditure (n=10, 7%).

### ***Risk of bias in included studies***

Of the included studies, 54% were deemed to have a low risk of bias and 46% were medium; a further 27 studies were excluded from this review as they were deemed to have a high risk of bias that was likely to alter their findings related to the relationship between disability and economic poverty.

Major sources of bias across studies included the lack of clearly defined, valid economic and/or disability measures. For disability measures, several studies measured disability through self-report of impairments or clinical diagnoses, or through a binary question on whether the respondent identified as disabled; both of these approaches are considered to underestimate the prevalence of disability, skewing estimates to more severe or “visible” forms of disability [19-21]. For economic measures, some metrics were inadequate to detect finer differences between populations that were mostly poor [22] or lacked sufficient validation.

Lack of adequate adjustment for confounding was also a concern, as, 20 studies (13%) were bivariate analyses only. Finally, low response rates and non-population based samples, were also sources of bias.

### **Association between disability and poverty**

Overall, the vast majority of studies (n=122, 81%) found evidence for a positive relationship between disability and poverty. The remainder was comprised of 23 studies (16%) that found no significant association, three (2%) that found a negative relationship and two with mixed findings. The study findings are disaggregated by study characteristics in Tables 3.

**Table 3. Association of poverty and poverty by study characteristics.<sup>10</sup>**

		Association of poverty with disability				
		<i>Positive</i>	<i>Null</i>	<i>Negative</i>	<i>Mixed</i>	<i>Total</i>
		%	%	%	%	N
<b>Overall</b>		81%	16%	2%	1%	150
<b>Disability/ impairment type<sup>a</sup></b>	Sensory impairment	78%	17%	0%	6%	18
	Physical impairment	80%	15%	5%	0%	20
	Intellectual/cognitive impairment	69%	31%	0%	0%	26
	Mental disorders	87%	11%	3%	0%	75
	General disability/functional limitations	80%	14%	3%	3%	35
<b>Disability measure<sup>a</sup></b>	Impairments	81%	16%	3%	1%	115
	Activity/functional limitations	79%	19%	0%	3%	33
	Mix	100%	0%	0%	0%	3
<b>Age group<sup>a</sup></b>	Children	78%	15%	0%	7%	27
	Adults	86%	12%	2%	0%	42
	Older adults	69%	27%	4%	0%	49
	Mixed ages	92%	8%	0%	0%	36
<b>Poverty indicator<sup>a</sup></b>	Income	83%	16%	0%	1%	82
	SES	81%	14%	3%	3%	36
	Assets	77%	20%	3%	0%	30
	PCE	60%	30%	10%	0%	10
<b>Region<sup>a</sup></b>	Latin America/Caribbean	60%	30%	10%	0%	60
	East Asia/Pacific	80%	17%	2%	2%	60
	Sub-Saharan Africa	51%	44%	4%	0%	68
	South Asia	79%	19%	2%	0%	42
	Middle East/North Africa	87%	7%	7%	0%	15
	Europe/Central Asia	36%	64%	0%	0%	14
	Multi-region	100%	0%	0%	0%	8
<b>Income group<sup>a</sup></b>	Low	59%	36%	4%	1%	95
	Lower-middle	67%	28%	5%	0%	100
	Upper-middle	72%	26%	1%	0%	69
<b>Gender<sup>a</sup></b>	Female	87%	14%	0%	0%	30
	Male	86%	14%	0%	0%	22
<b>Setting</b>	Rural	82%	18%	0%	0%	17
	Urban	79%	19%	2%	0%	52
	Both	83%	12%	2%	2%	82
<b>Risk of bias</b>	Low	88%	10%	1%	1%	81
	Medium	74%	22%	3%	1%	69

<sup>10</sup> Tables 2 & 3 as presented here are from the following correction issues on from the original published version. The correction can be found at: Banks, Lena Morgon, Hannah Kuper, and Sarah Polack. "Correction: Poverty and disability in low-and middle-income countries: A systematic review." *PloS one* 13.9 (2018): e0204881.

### ***Disaggregation by disability/impairment types***

The relationship between disability and poverty was apparent across all types of impairments/disability.

Of the 75 papers that focussed on mental disorder, 87% found evidence of a positive relationship with poverty. Papers in this category could be subdivided into depression/anxiety (n=31), common mental disorders [23] (n=12) and other (n=32). For depression, 26 papers found a positive association with poverty, a null association and one study found a negative association between lifetime prevalence of depression and assets in older adults in Nigeria, though the analysis was unadjusted by potential confounders. The relationship between common mental disorders and poverty was positive for ten studies, and null for the remaining two studies. For other mental disorders, 29 found a positive association, two found no association and one study found a negative relationship between per capita expenditure and psychiatric disorders.

Eighteen studies included analyses on sensory impairments, with 12 focusing on visual impairment, two on hearing impairment and three on both. Of these, 14 of 18 studies (78%) found a positive association with poverty. Additionally, three studies found no significant association between visual impairment and poverty; two of these studies performed unadjusted analyses only. One study in Vietnam reported mixed findings, with a positive association between hearing impairment and poverty, but a negative association with visual impairment.

Eighteen of the included studies evaluated the link between poverty and physical impairment. Fourteen of these studies (78%) found evidence of a positive association. The remaining four studies found no significant difference in poverty level between people with and without a physical impairment.

Among the 35 studies with more global measures of disability (e.g. mixed impairment types, functional limitations), 28 (80%) found a positive association with poverty and five studies found no significant difference in poverty between people with and without disabilities. Two studies reported mixed findings and one found a negative relationship.

There were 26 studies which reported on the association between poverty and intellectual/cognitive impairments, of which 69% found evidence of a positive relationship. Most studies in this category (n=16) focused on dementia and cognitive impairment in older adults. Of these, eight (50%) showed a null association. The other ten studies in this category (all but two of which were conducted in children), all found a positive association.

Eighty-nine studies disaggregated data by either levels of poverty or severity of disability. Of these, most (61 of 89, 69%) found the strength of the association between disability and poverty increased with increasing level of poverty/severity of disability. Four studies with negative associations also found a dose response relationship.

Finally, there was little difference between studies that used impairment-based measures of disability (93 of 114, 81%) compared to those that focused on activity or functional limitations (25 of 33, 79%).

### ***Disaggregation by study setting region and country income group***

By region, studies set in the Middle East & North Africa and East Asia & the Pacific countries were most likely to find a positive relationship between disability and poverty, with respectively 87% and 80% of analyses finding significant associations. In contrast, studies from Sub-Saharan Africa and Europe & Central Asia were least likely to report positive associations, with only 51% and 36% of analyses finding positive associations.

By country income group at the time of data collection, the proportion of country-level analyses with a positive association increased with the rising income level, with 59% of low-income, 67% of lower-middle and 72% of upper-middle income countries finding a positive relationship.

### ***Disaggregation by other factors***

By age group, the proportion of studies reporting a positive association between disability and poverty was lowest for older adults and highest for working-age adults (69% vs. 86%). Studies with mixed age groups – which comprised predominantly working-age adults – were mainly positive (92%).

The positive relationship between disability and poverty was consistent by economic indicator, though it was the least consistent for the nine studies using per capita expenditure as the measure (60% positive).

The majority of studies' settings included both rural and urban areas (n=83). For studies limited to either rural or urban settings, there was little difference in their findings on disability and poverty.

By risk of bias, studies with an assessed low risk were slightly more likely to find a positive association between disability and economic poverty (88% vs 74% for studies with a medium risk of bias).

Finally, while the majority of studies did not disaggregate by gender, for the 30 which did provide separate analyses for men and women (22 disaggregated studies, 8 studies among women only), the relationship between disability and poverty did not differ between men and women (86% vs 87% for men and women respectively).

### ***Evidence on directionality of association***

As 83% of the included studies are cross-sectional, it is difficult to ascertain the directionality of the association between disability and poverty in their analyses. The thirteen cohort studies and one pre-post study however, provide some indication. In all these studies, the focus was on how economic poverty impacted the risk of developing disability and all but one found that lower financial status was associated with an increased risk of developing a disability. Nine studies focused on development of mental disorders among different economic groups, with all but one finding a positive association. Additionally, three studies found a positive link between lower household income and developmental delay in children. Two studies on older adults reported individuals from poorer backgrounds were more prone to functional decline and dementia than their wealthier peers.

No longitudinal studies were identified that explored whether disability could lead to poverty.



### ***Association between disability and employment status***

While this review did not systematically explore the relationship between disability and employment, we did extract data from included studies as a scoping exercise to understand potential drivers of the relationship between disability and poverty.

In total, 35 of the studies included in this review assessed the relationship between disability and employment. Of these, 26 (74%) found a positive association (i.e. disability was significantly more common among non-employed versus employed groups or people with disabilities were significantly more likely to be non-employed compared to people without disabilities). The remaining eight studies found no significant association between employment status and disability, with one finding a negative association.

## **Discussion**

This systematic review finds strong evidence to support the link between disability and economic poverty, with 122 of 150 (81%) included studies reporting a statistically significant, positive relationship between these two variables. This large and comprehensive review therefore provides a robust empirical corroboration to the more theoretical arguments of a link between disability and economic poverty.

In addition to the large proportion of studies reporting a positive association between disability and economic poverty, other factors in line with the Bradford Hill criteria further substantiate the plausibility of a genuine link [24]. First, the observed relationship remained significant after authors adjusted for a range of confounders, such as age, gender, area of residence and level of education. Second, the trend of association was mostly consistent across regions, impairment types, study designs and age groups. Third, in the studies which disaggregated data by either levels of poverty or severity of disability, most (61 of 89, 69%) found evidence of dose response: namely, the strength of the association between disability and economic poverty increased with increasing level of poverty/severity of disability. Additionally, as explained through the disability-poverty cycle [2] and social determinants of health inequalities [4, 25], there are plausible mechanisms to explain how disability could contribute to economic poverty and vice versa.

Only five studies found a significant negative association (two of which were mixed) between disability and economic poverty [26-30], and these can be at least partially explained by mitigating factors. First, Pham et al found a significant negative relationship between visual impairment in children and household income, even though analyses of other impairment types in the study showed a positive association [26]. The finding was explained by the authors as likely resulting from additional schooling in wealthier households, with eyestrain from increased engagement in activities such as reading or using a computer heightening the risk of visual impairment. Second, Kuper et al. reported mixed findings on the association between disability and asset ownership in a multi-country study of children who were part of the Plan International Child Sponsorship Programme [27]. As criteria for entering into the programme is based on poverty and other forms of vulnerability, the comparator group of children without disabilities may have other characteristics (e.g. ethnic/religious/racial minority, orphans), which may be greater drivers of poverty compared to disability in certain contexts.

Third, Nakua et al. found arthritis/joint pain was more common in higher SES groups in Ghana; however this findings is likely explained by the measure of disability, which was self-report of a clinical diagnosis [28]. As poverty and poorer access to healthcare are linked [31], the observed association may be more reflective of the relationship between wealth and receiving needed medical attention. Fourth, Islam et al report an increase in psychiatric disorders with rising per capita household expenditures in Bangladesh [29]; the authors attributed this finding as potentially due to less familiarity and comfort with interview schedules used to ascertain psychiatric disorders among lower individuals from lower SES groups. Finally, Gureje et al. found a negative association between depression and asset ownership [30]; however, the analysis did not control for any potential confounders.

Twenty-three studies found no significant association between disability and economic poverty. However, eighteen of these studies found evidence of a positive relationship with other broader indicators of poverty (e.g. education, malnutrition, employment) not covered in this review [6, 32-48], indicating the value of more multi-dimensional approaches to studying poverty.

While overall the relationship between disability and economic poverty was consistent when disaggregated by a range of study characteristics, some variations were observed. For example, studies set in low-income countries or in certain regions (notably sub-Saharan Africa and Europe/Central Asia) were less likely to observe a relationship between disability and poverty. Some of this variation may be due to challenges accurately and appropriately measuring poverty in complex and varying economies. For example, in settings with high absolute poverty, differentiating between households or individuals may be challenging and the studies may have been under-powered to detect these small differences. Furthermore, accurately capturing true economic well-being in economies defined by the dominance of the informal sector, non-cash remunerated work, irregular flows of income and complex community-based resource sharing arrangements requires careful methodological consideration [49]. An alternative explanation for these trends is that people with disabilities are “left behind” as regions develop economically, so that the gap in poverty between those with and without disabilities will be larger in areas that are less poor.

Similarly, the strength of the relationship between disability and economic poverty differed slightly by age group. Analyses focused on older adults were slightly less likely to be positive (69%), compared to working-age adults (86%) and children (78%). In particular, dementia and cognitive impairment in older adults was not highly correlated with economic poverty (8 of 16 studies finding a positive association). If onset of disability occurs later in life, these individuals may have established more safeguards to protect against sliding into poverty than individuals who develop disabilities earlier in life and face exclusion throughout the life course. Additionally, as economic poverty has been linked consistently to lower life-expectancy [25], poorer individuals who survive into older age may be healthier than their wealthier counterparts.

While these findings provide clear evidence of correlation between disability and economic poverty, it is difficult in most cases to ascertain the direction of association given that 83% of the included studies are cross-sectional. Fourteen longitudinal studies [35, 50-60] - most of which focused on mental health conditions – assessed the risk of developing disability among different economic groups; all but one [35]

found a positive association, providing evidence supporting the social determinants of health theory [4, 25]. The findings for mental health in particular are corroborated by studies in high income countries [61], which find the daily stresses associated with lower social and economic position, combined with lower access to healthcare and other services, can increase the risk of mental health conditions.

The high proportion of studies showing a positive relationship between disability and economic poverty observed in this review stands in contrast to other reviews [9, 12], where findings were more mixed. Several factors may explain this difference. The search strategy for this study which used terms for both general disability as well as specific impairments/conditions and used systematic searching across multiple databases led to the inclusion of substantially more studies than either of the other reviews, thus greatly broadening the pool from which to draw evidence. Additionally, as the others used multidimensional conceptualizations of poverty whereas this review focused solely on the economic component, the divergence in findings may simply underscore the difference in definitions.

### ***Limitations***

There are some limitations that should be taken into account when interpreting the findings of this review. First, if studies showing a negative or null association were less likely to be published – resulting in publication bias – the association between economic poverty and disability could be overestimated. However, as most included papers were not focused explicitly on exploring the relationship between economic poverty and disability and instead either investigated this association as a secondary measure or as part of a multivariable analysis, it is unlikely that this source of potential bias was important. Second, we only focussed on economic definitions of poverty and did not include more multidimensional measures such as access to health, education or food security, which presents a limited view of poverty [62]. Third, as almost half of included studies were conducted in either Brazil, China or India, the findings of this review may be biased towards reflecting the conditions in those countries, which may differ from other LMICs. Similarly, other country-level factors that could affect the strength of the observed association – such as disability prevalence, availability and access to health and rehabilitation services, social protection and other supports – could not be included in the analysis as reliable,

comparable data on these indicators are not available in most countries. Fourth, since the majority of included studies (n=122, 83%) were cross-sectional, it was not possible to comment on the directionality of association in most cases, particularly of disability leading to decreased economic status. Fifth, the wide range of tools used to measure both disability and economic poverty – which varied in their sensitivity and validity – could affect the comparability and reliability of findings.

Finally, this review likely underestimates the full magnitude of the association between disability and economic poverty. Increasingly, experts are pointing to the need for an adjusted poverty line for people with disabilities to account for additional costs associated with disability incurred as a result of the need for assistive devices, personal supports, extra transport or higher medical/rehabilitation expenses [8, 63, 64]. As recognition of and methods for incorporating extra disability-related costs are underdeveloped, little evidence currently exists on relative poverty between people with and without disabilities taking into account this higher economic threshold needed to meet basic needs.

### ***Implications for future research***

#### ***On the relationship between disability and economic poverty***

While this review did identify a large number of studies exploring the relationship between disability and economic poverty, there is still need for further research in this area to understand how the relationship changes over time, place and between groups. To improve the quality of research in this area, there is a need for more standardised, robust measures of both disability and economic poverty to enable comparisons across contexts and over time. For example, a major source of bias in studies included in this review was the lack of detail on and reliability of economic poverty measures. This reinforces findings in Cooper et al's review on measuring poverty in psychiatric epidemiology, which highlights the pressing need for more critical and systematic approaches to assessments of poverty in varying contexts [22].

Longitudinal studies are particularly needed, especially in measuring the economic impacts after the development of disability as no study identified focused on this direction of association. Furthermore, as both disability and economic poverty are

dynamic and can fluctuate across the life-course, understanding the impact of these variations over time is also important.

### ***Other forms of poverty***

While economic poverty is a key metric for understanding and comparing well-being, deprivation and ability to meet basic needs, research exploring the relationship between disability and more multi-dimensional forms of poverty is also needed. By using a range of indicators – such as lack of education and engagement in decent work, inadequate living standards and poor health – multidimensional poverty may better capture the complexity of poverty and in turn assist in informing more nuanced strategies for poverty alleviation and disability prevention [62].

Furthermore, more research is needed on intra-household poverty. Most economic and many multidimensional measures of poverty use the household as the unit of analysis, which may obscure uneven distribution of resources or opportunities within the household [7]. For example, limited emerging research indicates that people with disabilities may fare worse compared to other household members on indicators such as malnutrition and access to education [46, 65]– which could be indicative of unequal allocation of resources or additional barriers to meeting basic needs among people with disabilities. Furthermore, additional research is needed on the extra-costs of disability. In particular, gaps in the evidence include: (1) the overall magnitude and sources of these costs, (2) whether individuals are actually able to afford and access all needed goods and services, and (3) the impact of these expense on functioning as well as social and economic well-being [64].

### ***“Causes of causes” and appropriate interventions***

While this systematic review has provided clear evidence of a link between disability and economic poverty, further research is needed to understand what Marmot calls the “causes of causes” [66]: the underlying social, political and economic conditions that give rise to the link between disability and economic poverty. Access to health (including rehabilitation), education and employment may explain some of the relationship between disability and economic poverty, potentially in both directions. While this review identified that people with disabilities were more likely to not be working, since work status was a secondary measure without specific search terms,

the observed association – as well as other potential drivers such as access to health and education – deserve further attention in separate systematic reviews. Understanding in greater depth how specific drivers impact the relationship between disability and economic poverty can help identify effective and appropriate interventions and strategies to break the cycle. To this end, attention will need to be given to how drivers vary among individuals and contexts, for example by gender, age and rural/urban settings.

Similarly, more research is needed to understand the impact of economic poverty on the lives of people with disabilities, as well as what existing interventions are effective at reducing poverty among people with disabilities. For example, exploring whether current poverty alleviation and social protection programmes are sufficiently disability-inclusive, as well as the impact of participation in both reducing disablement and/or decreasing poverty among people with disabilities is essential for policy and planning [67]. Similarly, given the finding in this review of a stronger association between disability and poverty as countries grow economically, it is critical to determine if and why people with disabilities are being “left behind” from the promise of economic growth and development.

## **Conclusion**

Failure to address the interaction between disability and poverty will undoubtedly stall economic growth and development, including in meeting the SDGs. With 81% of studies reporting a link between economic poverty and disability, the results of the systematic review provide a robust empirical basis to support the theorized disability-poverty cycle. Furthermore, as people with disabilities often incur additional expenses related to their disability (e.g. assistive devices, extra transportation) and thus may require a higher minimum threshold to meet basic needs [8], these findings likely underestimate the true extent of economic poverty among people with disabilities. Considering people with disabilities comprise upwards of 15% of the global population [5], neglecting to make poverty alleviation and development programmes disability-inclusive bars access to a substantial proportion of the population, significantly reducing their potential impact and enhancing inequalities.

## **Supporting information [see Appendix 6]**

**S1 Table. PRISMA checklist**

**S2 Table. Summarised extraction table**

**S1 File. Sample search string**

**S2 File. References of included studies**



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## ***Chapter 5. Disability and social protection programmes in low-and middle-income countries: a systematic review***

### **Preamble**

People with disabilities face a heightened risk of economic poverty, as highlighted in *Chapter 4, Paper 1*, and so social protection may be a critical tool for guaranteeing a minimum income, strengthening livelihoods and reducing economic inequalities. Other studies have also highlighted that people with disabilities face a heightened risk of multidimensional poverty (e.g. poor access to essential services, social exclusion) [1, 2]. Further, people with disabilities have the right to inclusion in social protection, as codified in the Universal Declaration of Human Rights (Articles 22 and 25), the UNCRPD (Article 28) and many national laws [3, 4]. Consequently, people with disabilities are frequently listed as key beneficiaries of social protection in national programmes and policies in LMICs, as well as in international frameworks [5, 6].

Given the emphasis on people with disabilities as a core target group of social protection [5], it is important to assess if programmes in LMICs are adequately reaching people with disabilities and what, if any, are the impacts of participation. Consequently, a systematic review was conducted to compile and evaluate available evidence on this topic, as well as highlight areas for future research.

The systematic review covered the published academic literature. It defined social protection as government-provided mainstream or disability-targeted social assistance and insurance schemes, and included programmes across LMICs. Overall, only 15 articles were retrieved which explored access to and impact of social protection amongst people with disabilities in LMICs, indicating that further research in this area is urgently needed.

This systematic review was published in the journal *Oxford Development Studies* in July 2017 after peer review. Web appendices can be found in Appendix 7 of this document.

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## Paper 2: Disability and social protection programmes in LMICs: a systematic review

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### SECTION A – Student Details

Student	Lena Morgon Banks
Principal Supervisor	Prof Hannah Kuper
Thesis Title	Investigating disability-inclusion in social protection programmes in low and middle income countries, with case studies from Vietnam and Nepal

*If the Research Paper has previously been published please complete Section B, if not please move to Section C*

### SECTION B – Paper already published

Where was the work published?	Oxford Development Studies		
When was the work published?	Feburary 2016		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	No	Was the work subject to academic peer review?	Yes

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Led on conceptualisation (development of methods, e.g. search strategy, inclusion/exclusion criteria), data collection, analysis. Wrote the original draft, which was reviewed by the other co-authors. Responsible for submitting to the journal and incorporating feedback from the journal's
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	peer review.
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Student Signature: \_\_\_\_\_

Date: Mar 12, 2019

Supervisor Signature: \_\_\_\_\_

Date: 26/7/19

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# Disability and social protection programmes in low- and middle-income countries: A systematic review

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## ABSTRACT

This paper systematically reviews the evidence on whether persons with disabilities in low- and middle-income countries are adequately included in social protection programmes, and assesses the financial and non-financial impacts of participation. Overall, we found that access to social protection appears to fall far below need. Benefits from participation are mostly limited to maintaining minimum living standards and do not appear to fulfil the potential of long-term individual and societal social and economic development. However, the most notable finding of this review is that there is a dearth of high-quality, robust evidence in this area, indicating a need for further research.

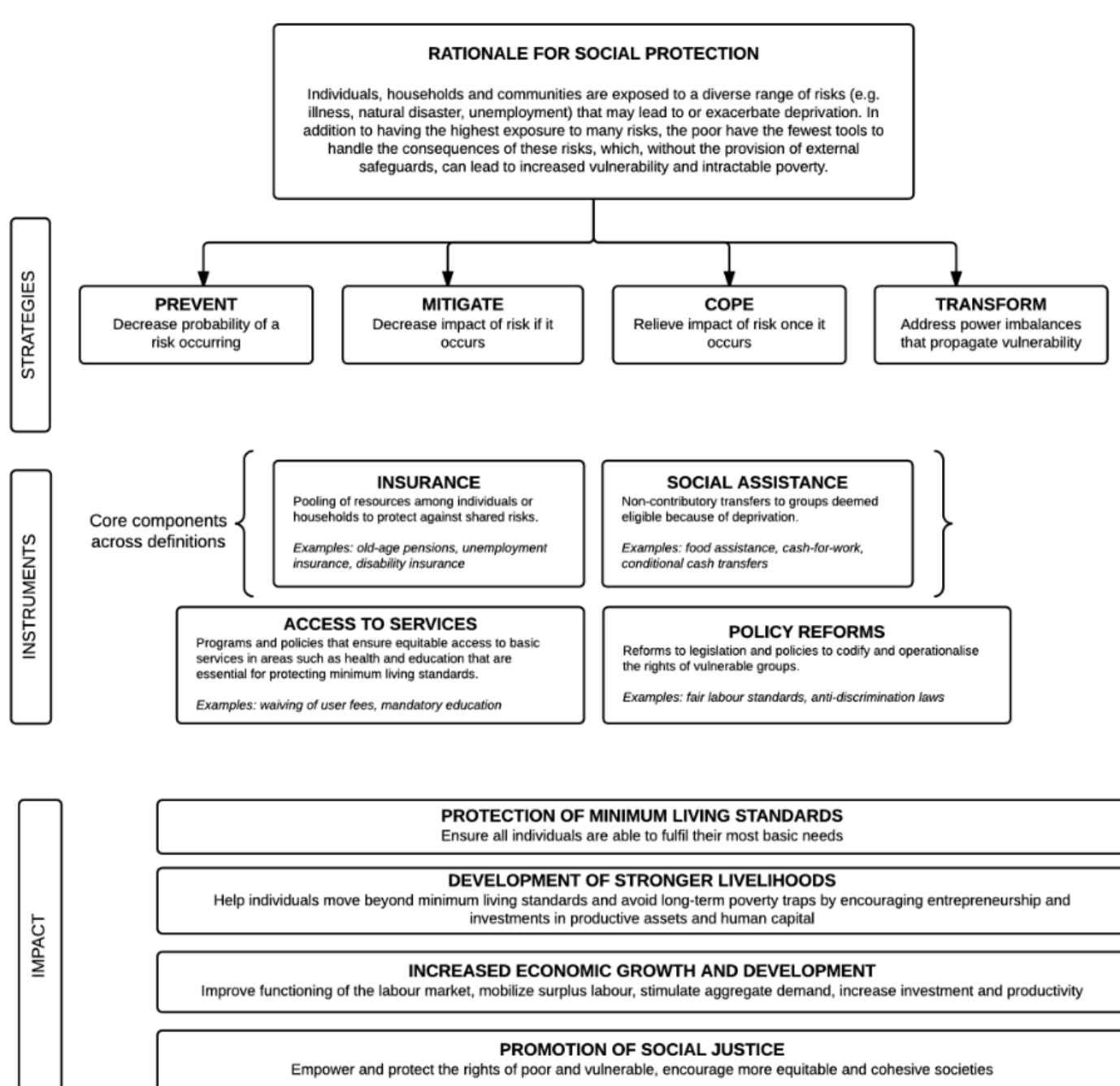
**Keywords:** disability, social protection, social assistance, insurance, vulnerability

## 1. INTRODUCTION

With the proliferation of development policies and programmes, there is an urgent need to collate and evaluate existing knowledge on their effectiveness. Establishing this evidence-base on “what works” can then inform decision-making in order to maximize desired outcomes. As a relatively new strategy in low- and middle-income countries [1], social protection has been rapidly gaining traction as a strategy and a set of instruments to prevent and alleviate poverty among individuals or groups vulnerable to deprivation [2, 3]. Given high levels of poverty and marginalization [4, 5], persons with disabilities are often explicitly or implicitly targeted by social protection programmes. However, little is known about whether persons with disabilities are being adequately included in existing social protection programmes or what the financial and non-financial impacts are on the lives of beneficiaries with disabilities from participation.

### ***1.1 Social protection framework***

Social protection is usually defined as actions to help individuals, households and communities prevent, mitigate or cope with risks which can temporarily or permanently lead to or exacerbate poverty and deprivation beyond a level considered acceptable in a given society [6] (see Figure 1).



**Figure 1: Social protection framework (adapted from Devereux & Sabates-Wheeler, World Bank, 2001)**

Though its central objective has been to protect minimum living standards so that all persons can meet their basic needs, social protection increasingly aims to promote a “springboard” or transformative function as well. This means that it intends to help individuals move beyond the subsistence level, so that they can invest in productive assets and human capital which allow for the development of stronger livelihoods and an escape from long-term poverty traps [3, 7, 8]. In the longer term, it is believed that the aggregate of these individual gains will lead to increased national economic growth and development as well as promote more equitable and cohesive societies [2, 3, 9].

Strategies listed under the umbrella of social protection to bring about these gains vary across frameworks. Typically, social assistance and insurance are seen as the dominant models for delivering social protection. In low- and middle-income countries, social assistance (i.e. non-contributory transfers in cash or kind to groups deemed eligible because of deprivation) has been the dominant model in use [1, 2]. Increasingly, however, forms of insurance (e.g. health insurance, old age pensions), previously more the purview of higher-income countries, are being adopted, particularly in middle-income countries [1]. Finally, under more extensive definitions, programmes and policies which ensure equitable access to basic services and reforms that protect the rights of vulnerable groups are being included as components of social protection [2, 3].

### *1.2 Social protection and disability*

Persons living in poverty or facing other forms of marginalization face higher exposure to many risks which could lead to or exacerbate poverty and vulnerability, but they often have fewer independent means at their disposal for preventing, mitigating or coping with these risks [7]. Social protection programmes thus often target individuals or groups considered particularly vulnerable to and from such risks. One such vulnerable group is persons with disabilities, who are significantly more likely to be living in poverty and face a wide-range of social, economic and cultural forms of exclusion [5]. Consequently, many social protection schemes either implicitly or explicitly include persons with disabilities in their eligibility criteria. Complementing this needs-based argument for disability-inclusive social protection, the right to social protection for persons with disabilities is enshrined in the Universal

Declaration of Human Rights (Article 25: the right to adequate standards of living and security) and the United Nations Convention on the Rights of Persons with Disabilities (Article 28: adequate standards of living and social protection).

The combination of these arguments provides the normative basis for efforts to achieve the full inclusion of persons with disabilities within social protection policies and programmes at the global, regional and national level. There are a number of international frameworks for social protection – including the Social Protection Floor initiative by the International Labour Organization with endorsement from the World Health Organization, various United Nations bodies, the World Bank, donor agencies, non-governmental organizations and others [10]. Whilst these frameworks recognize the needs and rights of persons with disabilities to social protection, comprehensive strategies beyond simply identifying persons with disabilities as a vulnerable group are lacking.

The absence of clear strategies for making social protection disability-inclusive may lead to the exclusion of persons with disabilities. As evidenced with the Millennium Development Goals - which made no reference to disability in any of its Goals, Targets or Indicators - failure to address barriers to inclusion may propagate the continued economic and social marginalization of persons with disabilities [11]. Specific barriers which prevent persons with disabilities from accessing and realizing the benefits of social protection programmes may include: inaccessibility of administration and service procedures and centres, discriminatory attitudes of administrators, certain conditions attached to receipt of benefits (e.g. school attendance) and limited awareness of the availability and eligibility for programmes [12].

Furthermore, the use of a standard income-based poverty line for assessing eligibility in all applicants and the provision of fixed benefits to all recipients may mask actual levels of need of persons with disabilities. Notably, as persons with disabilities often encounter additional disability-related expenses (e.g. extra transport, medical and rehabilitation costs, purchase of assistive devices), they tend to have higher expenditure needs than people without disabilities [13, 14]. Persons with disabilities may then have to forgo or decrease consumption of essential items and services if unable to sustain these extra expenses. For example, in low-income

countries, persons with disabilities are over 50% more likely than people without disabilities to cite costs as a reason for not accessing needed health care [5]. In the long-term, paying out-of-pocket or forgoing essential expenditures can lead to further restrictions in participation in areas such as school and employment and may impede the development of human capital, reduce household earnings and ultimately keep individuals in long-term poverty traps (World Health Organization, 2001). Therefore, social protection programmes may need different eligibility criteria and benefit packages for recipients with disabilities [12]; failure to incorporate this in the programmes may lower access and reduce the impact of social protection programmes for persons with disabilities.

Given the emphasis placed on social protection as an important development tool for spurring and equalizing social and economic growth – particularly for vulnerable groups such as persons with disabilities – there is a pressing need to determine whether these programmes are adequately reaching persons with disabilities and whether participation is producing the desired impacts among this group of target beneficiaries. To address this gap in knowledge, we use a systematic review methodology to select, assess and analyse the published evidence on access to and impact of social protection among persons with disabilities in low- and middle-income countries. Through this process, we explore questions such as whether existing programmes are sufficiently disability-inclusive, and how to better tailor programmes and policies for full and effective inclusion of persons with disabilities not just within social protection programmes themselves but also in the broader processes of social and economic growth.

## **2. METHODS**

While systematic reviews are relatively new in the field of international development [15], this method is well-established within medicine, public health and social science as a robust and transparent means of gathering, summarizing and evaluating existing evidence on a given topic [16]. By striving to produce a comprehensive, objective overview of available research, systematic reviews can then be used to guide policy decisions or identify priorities for further research if evidence is lacking.

This systematic review was conducted in line with standard procedures as outlined in the PRISMA statement, the evidence-based, expert-endorsed guidelines for systematic review methodology[16].

## **2.1 Search strategy**

Eight electronic databases relevant to the topic of disability and social protection were searched between July-December 2014: Web of Science; EconLit; ERIC; ProQuest Health and Medicine Complete; ProQuest Political Science; Pro Quest Research Library; ProQuest Social Science Journals; and ProQuest Sociology. Additional sources were then identified through searching the reference lists of included studies and by recommendations from experts in the fields of social protection and/or disability.

Search terms for disability, social protection and low- and middle-income countries were identified through MeSH as well as from other reviews on similar topics [17] (for full search string, see web annexes). Searches were limited to English-language titles, and to capture more recent trends, the date of publication was restricted to 1990 onwards.

## **2.2 Inclusion/exclusion criteria**

Any peer-reviewed article presenting original research which focused on access to or impact of social protection programmes among persons with disabilities in low- and middle-income countries was eligible for inclusion. For the purpose of this paper we focused on publicly provided social assistance and insurance schemes, as these components form the core of social protection across the varying definitions. We included both mainstream programmes (i.e. persons with disabilities not explicitly specified as intended beneficiaries but implicitly targeted due to higher levels poverty and other types of vulnerability) and targeted programmes (i.e. those where disability is an explicit criteria for eligibility). Studies and social protection programmes defining disability using both medical model definitions of disability (i.e. specific impairments or disorders) as well as broader classifications (e.g. functional or activity limitations, participation restrictions) were eligible for inclusion.

No restrictions were placed on study design, with papers using either quantitative or qualitative methods eligible for inclusion.

### ***2.3 Papers selection, screening and quality assessment***

Articles were screened sequentially by abstract, title and full text by two of this paper's authors to determine inclusion in the final sample. To evaluate the risk of various types of bias in the included studies, articles were separately evaluated by two of this paper's authors using modified versions of the assessment tools RATS and STROBE, for qualitative and quantitative studies, respectively [18, 19] (for list of assessment criteria, see web annexes). Assessment focused on the risk of potential biases arising from study design, sampling methods, data collection and data analysis/interpretation. Studies were categorized as: (1) "low" risk of bias if all or almost all of the criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study; (2) "medium" risk of bias if some of the assessment criteria were fulfilled, but those not fulfilled were thought unlikely to alter the conclusions of the study; or (3) "high" risk of bias if few or no criteria were fulfilled, and the conclusions of the study were thought to potentially be altered with their inclusion. As this was a broad review – with included studies varying widely in terms of research questions, methodologies used, study populations and outcomes measured – no strict cut-offs were used in assigning classifications; instead, papers were holistically evaluated to assess their overall risk of bias. Differences between reviewers in categorizations for the quality assessment were discussed and a consensus in ranking was reached on all papers.

### ***2.4 Data extraction and analysis***

The following information was extracted from studies included in the final sample:

- Study characteristics (design, site of recruitment, location)
- Study population characteristics (disability/impairment type, composition of comparison group, size, age range, gender)
- Characteristics of social protection programmes (type, implicit or explicit targeting scheme)
- Research outcomes (main findings related to access to and impact of social protection for persons with disabilities)

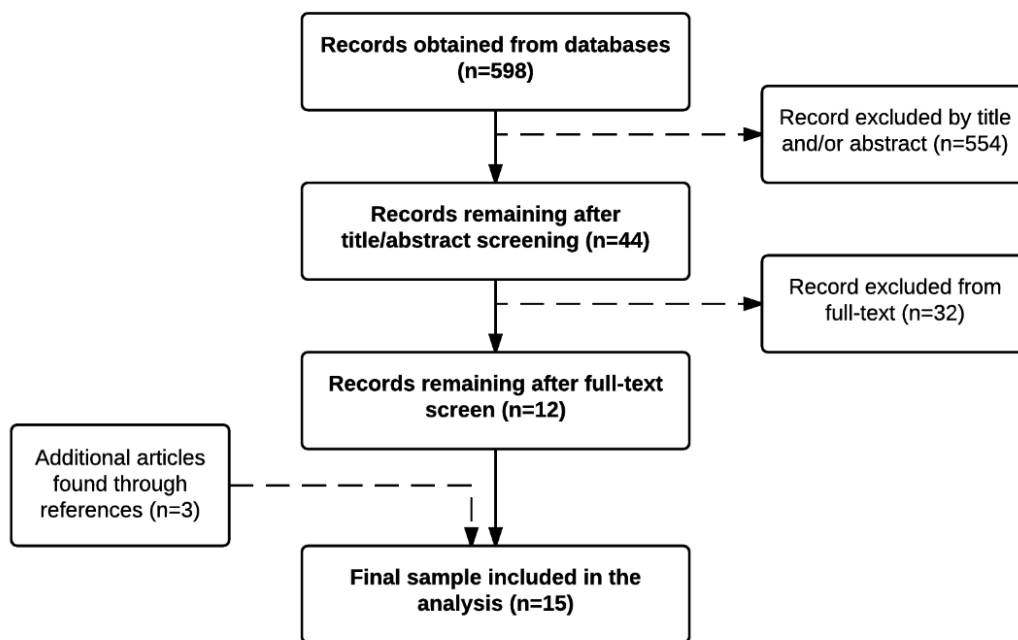
In classifying study outcomes related to the impact of social protection in extraction tables, if participation in a particular programme produced any evidence of a desirable outcome in a particular domain (e.g. decreased barriers in meeting basic needs, reduction in poverty, increased employment), then that programme was deemed to have a positive impact. If participation led to undesirable outcomes (e.g. increased unemployment, poverty), the programme was classified as having a negative impact. Social protection programmes were also classified as having no impact if participation did not result in discernible changes among recipients, and as having mixed impact if the programme led to a combination of positive and negative outcomes.

For studies using a comparison group (e.g. social protection recipients with disabilities compared to participants without; recipients versus non-recipients with disabilities) all impacts were classified in relation to the comparator.

### **3. RESULTS**

Searches of the electronic databases yielded 598 records, of which 554 were rejected in screening by title or abstract. After a further 32 articles were excluded after reviewing their full text and an additional 3 articles added through expert recommendations or from searching the reference lists of other studies, a final selection of 15 studies was obtained (see Figure 2).





*Figure 2: Flow chart of included studies*

### **3.1 Description of the studies**

All included studies were published in 2004 or later, reflecting the recent interest in this area. By study location, approximately half of the studies (n=8, 53%) were conducted in South Africa, with the remainder based in China (n=2), Vietnam (n=3) and Namibia (n=1). One study was a multi-country analysis (Argentina, Brazil, Colombia).

By study design, most were quantitative (n=11, 73%), of which all but one (an ecological study) used cross-sectional surveys. Three studies were purely qualitative and one used mixed methods.

Concerning types of social protection programmes (see Table 1), most studies focused solely on social assistance (n=10, 67%), of which nine were programmes targeted to persons with disabilities and one examined both targeted and mainstream structures. Three articles focused on insurance (health insurance, pensions), and two covered a mix of social protection schemes.

**Table 1: Description of social protection programmes in included studies**

<i>Citation</i>	<i>Setting</i>	<i>Type of social protection</i>	<i>Description of programme</i>	<i>Name of programme</i>
Berry & Smit (2011)	South Africa; unknown if rural or urban	Social assistance, targeted and mainstream	Non-contributory cash transfer to caregiver of a child with a severe disability	South African Care Dependency Grant
Goldblatt (2009)	Rural and urban South Africa	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Grant
Graham et al (2012)	Urban South Africa	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Grant
Jelsma et al (2008)	Urban and rural South Africa	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Grant
Levine et al (2011)	Namibia (national)	Social assistance, targeted	Non-contributory cash transfer to individuals over 16 with temporary/permanent disability; no minimum means requirement	Namibian Disability Grant
Li et al (2013)	Urban and rural China	Insurance (pension), targeted	Old-age pensions (no further details)	Not stated
Loyalka et al (2014)	China (national)	Social assistance and insurance, mainstream	Social assistance: minimum life allowance, relief assistance; Insurance: pension, medical, unemployment, maternity, work accident insurance, rural cooperative medical and pension insurance	Not stated
Macgregor (2006)	Urban South Africa	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Granted
Mitra (2008)	South Africa (national)	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Grant
Mitra (2010)	South Africa (national)	Social assistance, targeted	Non-contributory cash transfer to adults living in poverty, found medically unfit to work (permanently or temporarily)	South African Disability Grant
Palmer & Nguyen (2012)	Vietnam (national)	Insurance (health), mainstream and targeted	Non-contributory insurance for severe disability, incapacity to work and without a source of income; other non-disability targeted schemes for poor (non-contributory) or general population (contributory)	Compulsory Health Insurance, Voluntary Health Insurance or Health Insurance for the Poor
Palmer et al (2012)	Vietnam (national)	Social assistance and insurance (health), mainstream	Non-contributory health insurance, cash transfers	Not stated
Palmer (2014)	Vietnam (national)	Insurance (health)	Health insurance, both contributory and non-contributory (depending on poverty, disability status)	Social Health Insurance
Saloojee et al (2007)	Peri-urban South Africa	Social assistance, targeted	Grant to adults living in poverty, found medically unfit to work	South African Disability Grant
Vazquez et al (2011)	Argentina, Brazil, Colombia	Social assistance, targeted	Grant to caregiver of a child with a severe disability	South African Care Dependency Grant

While most studies included participants with all types of disabilities (n=12, 80%), some focused on specific impairments (n=3).

From the quality assessment, five studies were ranked as having low, six as medium, and four as high risk of bias. Most sources of potential bias arose from the sampling methods, with small samples sizes, non-population based sources and convenience strategies for recruitment, limiting the generalizability of results. Specific sources of potential bias can be found in the web annexes and the implications of these sources of potential bias are discussed in more detail throughout the paper.

### ***3.2 Access of persons with disabilities to social protection***

Eight studies presented findings on barriers faced by persons with disabilities in accessing social protection programmes (see Table 2). All but one study [20] in this category refer to targeted social assistance programmes in South Africa.

*Table 2: Access to social protection programmes*

Source of evidence				Measure of access		Barriers to and differences in access
Citation	Study design	Setting	Source of sample	Type of social protection	Indicator	
Berry & Smit (2011)	Cross-sectional	South Africa; unknown if rural or urban	18 children with disabilities or chronic illness (recruited from tertiary care centres)	Social assistance, targeted and mainstream		Assessment instrument discriminates against chronic illnesses, temporary health conditions and mild/moderate disabilities  Administration difficulties (e.g. complicated grant process, individuals not aware they're eligible, inconsistencies between provinces in administration practices/procedures), inaccessible facilities (pay points, offices), problems with assessment panels (subjective, lack of confidentiality/respect), additional expenses (for application, transportation, assistance, childcare), safety concerns especially for women when accessing pay points
Goldblatt (2009)	Qualitative	Rural and urban South Africa	93 individuals, including experts and people with disabilities (recruited from clinics, grant offices)	Social assistance, targeted		Not having correct documentation, inability to access the grant offices, not knowing how to apply and lack of clarity from health professionals about type and severity of disability and the impact it has on his/her work.
Graham et al (2012)	Mixed methods	Urban South Africa	94 people with disabilities (population-based recruitment)	Social assistance, targeted		No differences between recipients and non-recipients with disabilities in age, gender, marital status, impairment type or employment status. Recipients were significantly more likely to live in rural areas and report a mobility limitation.
Jelsma et al (2008)	Cross-sectional	Urban and rural South Africa	305 people with cognitive, physical or sensory impairments (population-based recruitment)	Social assistance, targeted		Patients not always aware of procedures for being assessed for a disability grant; patients felt they would be more likely to receive the grant if they were on medication; medical staff felt patients should find own solutions to their economic problems rather than seeking a disability grant; disability grant was withheld until patients were compliant with medication.
Macgregor (2006)	Qualitative	Urban South Africa	Observations from a psychiatric clinic involved in disability grant assessments	Social assistance, targeted		Disability grant recipients are significantly more likely to have a work disability and be older, substantially less educated and three times more likely to be illiterate compared to non-beneficiaries.
Mitra (2010)	Cross-sectional	South Africa (national)	General Household Survey 2005	Social assistance, targeted	1. Exclusion error rate 2. Inclusion error rate	1. 42% 2. 34%
Palmer & Nguyen (2012)	Cross-sectional	Vietnam (national)	National survey of 158,000 individuals	Social assistance/health insurance, mainstream	1. Coverage among people with disabilities 2. Exclusion error rate	1. 19% 2. 66.4-80.1%
Saloojee et al (2007)	Cross-sectional	Peri-urban South Africa	Caregivers of 156 children with disabilities	Social assistance, targeted	Percentage of eligible children receiving grant	Unaware that child qualifies (29%), lack of documentation (28%), administration/bureaucratic obstacles (20%)

N.B. Blank spaces indicate that particular study did not assess the given measure.

Three studies in the final sample included quantitative measures to gauge access among persons with disabilities, with all finding evidence of exclusion [20-22]. Both Mitra. (2010) and Palmer & Nguyen (2012) analysed national survey data to estimate exclusion error rates; that is, the percentage of eligible individuals who are not participating in a given social protection programme. Mitra (2010) reported a high rate of exclusion from disability grants in South Africa, with 42% of eligible individuals not enrolled. The inclusion error rate was also high (34%) – indicating problems in the sensitivity of targeting; however, authors noted that exclusion errors were more serious, as excluded households fared worse in terms of food security [21]. Palmer & Nguyen (2012) also noted that the exclusion rate from mainstream health insurance in Vietnam was high, as 66-80% of eligible persons with disabilities were not enrolled. Similarly, Saloojee *et al.* (2007) found in a smaller cross-sectional study in South Africa that only 45% of eligible families with children with disabilities were receiving care dependency grants. No studies provided measures of equity in coverage between people with and without disabilities, although Palmer & Nguyen (2012) noted that the percentage of persons with disabilities accessing health insurance in Vietnam was similar to the total population (19%). However, this figure only indicates the proportion of total population – not the eligible population – and thus persons with disabilities may still have lower access relative to need.

In the two studies exploring differences in characteristics between persons with disabilities receiving and not receiving social protection, no common themes were evinced. In South Africa, recipients of social protection programmes were significantly more likely to be older, have a disability resulting from work and be less educated than non-recipients [21]. In a separate study from South Africa, living in a rural area and having an impairment which limited mobility were associated with better access to social assistance [23]. However, no differences were found in age, gender, impairment type, marital status and employment status when comparing recipients and non-recipients with disabilities.

The most commonly cited barrier to accessing social protection programmes related to disability assessment processes for targeted social assistance programmes [22, 24-27]. Means of assessing disability were deemed subjective, with evaluators commenting on a lack of clear assessment criteria with which to judge applicants

[27]. Consequently, some authors noted that assessments excluded persons with certain types of disabilities, such as chronic conditions and temporary, mild or moderate disabilities, instead only picking up severe and highly visible forms of disability [24]. Furthermore, applicants often were unclear about how decisions were made and felt discriminated against by evaluators [23, 27, 28]. Lack of confidentiality and respect for applicants during the assessment process was also reported [25].

Difficulties with the application process were also commonly reported as a barrier to access [22, 25, 27, 28]. Persons with disabilities were frequently unaware of the existence of certain programmes or that they met eligibility criteria [25, 27, 28]. Additionally, respondents reported being unclear on application requirements, lacking correct documentation or having difficulties accessing grant offices [22, 25, 27, 28]. Bureaucratic complications, such as inconsistent policies and practices between regions, were also noted [25]. Finally, in addition to application fees, some participants reported incurring expenses while seeking social protection which were prohibitive for them – for example, for transport, child care, or assistance [25].

Even when accepted into a social protection programme, some struggled to receive benefits. Inaccessible pay points posed problems, even if they were physically close to recipients; additionally, safety was a concern, particularly for women, when attending pay points to collect stipends [25].

### ***3.3 Impact of social protection for beneficiaries with disabilities***

Twelve studies presented findings on the impact of social protection for persons with disabilities (see Table 3).

**Table 3: Impact of social protection on poverty, employment, health access and mental health**

Source of evidence				Evidence of Impact						
Citation	Study design	Setting	Source of sample	Type of social protection	Comparison	Meeting basic needs	Reducing poverty	Employment	Health access	Mental health
Berry & Smit (2011)	Cross-sectional	South Africa; unknown if rural or urban	18 children with disabilities or chronic illness (recruited from tertiary care centres)	Social assistance, targeted and mainstream	Non-recipients with disabilities	+				
Goldblatt (2009)	Qualitative	Rural and urban South Africa	93 experts, including people with disabilities (recruited from clinics, grant offices)	Social assistance, targeted	None	+	No effect			-
Graham et al (2012)	Mixed methods	Urban South Africa	94 people with disabilities (population-based recruitment)	Social assistance, targeted	None	+	No effect			
Jelsma et al (2008)	Cross-sectional	Urban and rural South Africa	305 people with cognitive, physical or sensory impairments (population-based recruitment)	Social assistance, targeted	Non-recipients with disabilities			No effect		
Levine et al (2011)	Cross-sectional	Namibia (national)	2003-2004 Namibia Household Income and Expenditures Survey	Social assistance, targeted	Non-recipients with disabilities	+	+			
Li et al (2013)	Cross-sectional	Rural and urban China	826 individuals over 60 either bedridden or with dementia (population-based)	Insurance (pension), targeted	None	+				
Loyalka et al (2014)	Cross-sectional	China (national)	National Survey of Disabled Persons (2006)	Social assistance and insurance, mainstream	None	+	No effect		Mixed	
Mitra (2008)	Ecological study	South Africa (national)	General Household Surveys (2002-06), October Household Surveys (1998-99)	Social assistance, targeted	All people with disabilities in South Africa			-		
Mitra (2010)	Cross-sectional	South Africa (national)	General Household Survey 2005	Social assistance, targeted	Non-recipients with disabilities	+		-		
Palmer et al (2012)	Cross-sectional	Vietnam (national)	27 households with a member with a disability (population-based)	Social assistance and insurance (health), mainstream	None	No effect			Mixed	
Palmer (2014)	Cross-sectional	Vietnam (national)	2006 Vietnam Household Living Standards Survey	Insurance (health)	Other recipients without disabilities		Mixed		+	
Vazquez et al (2011)	Cross-sectional	Argentina, Brazil, Colombia	241 individuals with bipolar disorder (recruited from inpatient/outpatient programmes)	Social assistance, targeted	Non-recipients with disabilities					-

N.B. Blank spaces indicate that particular study did not assess the given measure.

### 3.3.1 Impact on poverty: meeting basic needs and reducing poverty

Seven of eight studies found that inputs from social protection played an important role in helping individuals and their households meet basic needs [21, 24, 25, 28-33]. Beneficiaries often pointed to the vital role that social protection played in helping their household cope financially – for buying essential items such as food, clothes, electricity and basic healthcare – which they would otherwise struggle to afford. However, not all programmes were sufficient to protect minimum living standards for recipients: for example, in Vietnam, the value of cash transfers was found to be inadequate in covering minimum daily food intakes of persons with disabilities [29].

In assessing whether social protection could help persons with disabilities to escape poverty, findings were less positive. Though one multivariate analysis of national survey data in Namibia found that participation in various social protection programmes significantly reduced a person with a disability's probability of living in a poor household [30], most studies indicated that social protection contributions were insufficient to provide an escape out of poverty [25, 26, 32, 34]. Notably, social protection schemes failed to cover disability-related expenses – such as assistive devices, extra medical and transport costs – which were often a significant financial burden to households [25, 28, 32, 34]. Disability-associated costs can be substantial – one included study found them to account for 18-31% of total household income (Loyalka et al., 2014) – and reduce the standard of living for a given income threshold. The failure of programmes to compensate the extra associated costs with disability may propagate economic inequalities between recipients with and without disabilities: for instance, in Vietnam, although health insurance protected against catastrophic health expenses, compared to other groups persons with disabilities were at increased risk of poverty due to continual out-of-pocket expenditures for items not covered in their plans (e.g. medication, specialized services, transport) [34].

### 3.3.2 Impact on healthcare access, mental health and employment

Seven studies [23, 25, 29, 32-35] examined the impact of social protection in domains other than poverty.



Evidence from three studies examining healthcare access was mixed, but indicated that health insurance schemes were inadequate in covering the healthcare needs of recipients with disabilities. For example, although health insurance in Vietnam significantly increased recipients with disabilities' use of health services [34], there were some issues around the sufficiency of coverage, particularly in comparison to recipients without disabilities. While health insurance was found to help recipients cope with minor health issues, for instance, it was insufficient to cover more complex health care needs, which persons with disabilities may be more likely to require [29]. Consequently, persons with disabilities reported spending four times more on healthcare – even with insurance – compared to other groups without disabilities [34]. Similarly, in China, health insurance recipients with disabilities reported that only 18% of their medical expenses were covered [32].

Additionally, evidence from two studies indicated that there may be some negative mental health impacts associated with receiving social assistance. For example, a multi-country study found that among people with bipolar disorder, receiving targeted social assistance was significantly associated with increased self-perceived stigma [35]. Additionally, participants in one study noted that while social assistance was integral to their household's economy, fear of losing the grant caused emotional distress [25].

Finally, some experts have questioned whether social assistance deters engagement in work: in analysing national survey data in South Africa, it was found that a 10% increase in coverage of disability was associated with a 15% drop in employment rates among persons with disabilities [33]. However, a smaller study found no difference in employment status between recipients and non-recipients with disabilities [23].

#### **4. DISCUSSION**

Perhaps the most notable finding of this review is that there is a dearth of high quality, robust evidence which comprehensively evaluates access to and impact of participation in social protection programmes for persons with disabilities in low- and middle-income countries. The research and policy implications emerging from the existing evidence gathered from this systematic review is discussed below.

#### *4.1 Access to social protection*

Studies exploring access of persons with disabilities to social protection found evidence of exclusion. For example, from the exclusion error rates provided in two studies (Mitra, 2010; Palmer & Nguyen, 2012a), it appears that many eligible persons with disabilities are not covered in existing social protection programmes. In addition to evaluating overall access, it is important to determine equity in access, both among persons with disabilities and in comparison to the broader eligible population for mainstream programmes; however, no study in this review measured relative access between eligible persons with and without disabilities, indicating an area in urgent need for further research. For differences in access among persons with disabilities, there is some indication that persons with impairments affecting mobility [23] or which are work-related [21] are more likely to receive disability grants in South Africa. This may reflect biases in the assessment process towards ‘visible’ and ‘socially acceptable’ forms of disability, though more evidence is needed.

It should be noted that few studies provided robust, programme-wide measures on access of persons with disabilities to social protection. Much of the evidence came from small-scale qualitative studies and thus the evidence provided is often anecdotal, with limited generalizability. From a research perspective, measuring access presents several methodological challenges. To determine coverage among persons with disabilities, information on both the percentage of persons with disabilities in the overall population and the proportion who are enrolled in social protection programmes is needed. Then, to establish if a programme is sufficiently reaching its target beneficiaries, data on the percentage of persons with disabilities who meet eligibility criteria for a particular programme in the catchment population will also be required. However, it may be difficult to find accurate, reliable estimates for this [36], especially in mainstream schemes which may not record the disability status of participants. One approach has been to extrapolate survey or census data; however, this method may have limitations as national data collection often suffers from inaccuracies and incompleteness, and measurements of factors such as disability and poverty may be inconsistently measured across sources [36].

Nevertheless, from a policy perspective, a clear finding from this review is the need for improved design and implementation of social protection eligibility in order to

avoid the exclusion of persons with disabilities who, based on need, should actually be included in programmes [24, 25, 27, 28]. For example, a key criteria, particularly for social assistance, is that recipients are below a certain poverty threshold, which is usually based on income [12]. However, few programmes account for the extra costs of disability, which can substantially deplete a household's income and lower standards of living. Without this adjustment, assessments of the number of households or persons with disabilities who are living in poverty will likely be underestimated [32, 37].

Similarly, tailoring of disability assessments to determine eligibility in targeted social protection programmes is needed to ensure contextually appropriate approaches which do not lead to the exclusion of persons with certain types of disabilities. Although often assumed to be an “easily identifiable trait” similar to age or sex [12, 38], determining who has a disability is complex. Definitions of disability employed in assessments vary widely: some models take a more medical approach of focusing on specific impairments, while others attempt to incorporate a social model which views the disability as resulting from inaccessible societies where the physical, cultural and policy environments are not accommodating of individuals with functional limitations or impairments. Both models present difficulties in assessing disability for eligibility in social protection programmes. For example, assessments with medical model criteria – which currently most social protection programmes tend to use – may be biased against invisible or episodic impairments (e.g. some mental health disorders) and require trained personnel and medical services, which may be unavailable or insufficient in certain settings [12]. Attempts to incorporate social model approaches (e.g. measuring the ability to function within a given environment) have been criticized as being too subjective and open to fraud [13, 39]. Within the disability literature, defining disability in line with the International Classification of Functioning, Disability and Health (ICF), which attempt to combine both medical and social approaches, is generally preferred; use of ICF in social protection eligibility assessments has thus far been limited, due in part to complex assessment procedures difficult to implement at the programme level [12].

Finally, other criteria attached to eligibility are often difficult to assess [12]. For example, many schemes include stipulations that the disability causes an individual

to be “unable to work”, a determination which is highly subjective and may rely more on external social, environmental and personal factors than on limitations posed by a specific impairment [12]. Consequently, many persons with disabilities who would otherwise be targeted for inclusion may not be recognized as having a disability according to the programme criteria, putting into question whether those programmes are reaching the most vulnerable.

#### *4.2 Impact of social protection*

Referring to the intended impacts of social protection outlined in Figure 1, evidence from this review indicates that actual impacts among recipients often fall short in certain domains.

In the most central function of protecting a minimum living standard, the majority of included studies indicated that social protection programmes performed well. All but one study [29] found that social protection played an important role in helping recipients meet their most basic needs.

However, in assessing the ability of social protection to help beneficiaries move beyond a subsistence level, develop stronger livelihoods and ultimately escape poverty, findings were more mixed. Only one study [30] indicated that access to social protection decreases the likelihood of living in poverty, while all others found no or mixed effects. The failure of social protection programmes to account for extra costs associated with disability was cited as a major reason for their limited impact [25, 28, 32, 34]. Not only can disability-associated expenses be substantial [32], but when financial constraints lead to the forgoing of these often-essential expenditures, the ability to develop stronger livelihoods and escape poverty may be hindered in the long-term. For example, not purchasing assistive devices or accessing needed medical care can worsen activity limitations, which in turn restrict participation in areas such as school or work. Not accounting for these extra costs when designing benefit packages could therefore minimize the potential of social protection as a tool for long-term poverty alleviation and development.

In addition, some studies indicated a deterrent effect on employment, likely arising from stipulations in eligibility criteria that beneficiaries be ‘unfit to work’ [33]. As employment leads to income generation and typically greater economic self-

sufficiency, dissuading beneficiaries from engaging in work undermines the ability of social protection to foster more sustainable, gainful livelihoods and may lead to longer dependence on benefits [14].

Similarly, unmet health needs can propagate long-term poverty and impede livelihood development [40]. Although social protection – particularly health insurance – has been cited as a means of lowering barriers to accessing needed health services, findings from this review on its impact for persons with disabilities were mixed. Most studies indicated that, although insurance provided some benefits, coverage was typically insufficient to meet the full range of health needs of recipients with disabilities. This inadequacy was particularly apparent when analysed in relation to maintaining similar levels of health [41], failure to target benefit packages to fit the needs of persons with disabilities may limit the potential of social protection to alleviate poverty and lead to the propagation of health and income inequalities.

Concerning whether the more lofty goals of promoting social justice and spurring economic growth and development are being met, evidence is non-existent. While it may be assumed that reducing poverty and increasing the social and economic participation of persons with disabilities could lead to aggregate gains on a larger scale, no studies provided empirical corroboration. Similarly, although no included studies explicitly examined the impact of social protection on promotion of social justice, some evidence indicates that this goal is far from being fulfilled. For example, findings related to mental health and social protection – such as that persons with bipolar disorder on social protection experienced higher rates of stigma compared to non-recipients [35] – would seem to counter aims of social protection as a vehicle for empowerment and reduced marginalization. Furthermore, the one study comparing impacts between recipients with and without disabilities [34] highlights issues in equity: as benefits of participation were not shared equally between groups, it suggests that social protection, if not targeted properly, may continue to propagate social inequality.

#### *4.3 Limitations of the review*

Several limitations should be taken into account when interpreting the findings of this review. Firstly, there was extremely limited data available as very little has been

published on this topic. Where available, over half of included studies were based in South Africa, which is an upper middle-income country [42] and has a relatively well-developed, comprehensive social protection system [43]. This means that findings may not be generalizable to the situation in other low- to middle-income countries. More research from other countries and regions, with different social protection schemes, would be useful for enriching the evidence base, enabling comparisons across diverse contexts and ultimately increasing the power with which to guide policy decisions.

Furthermore, only a third of included studies could be ranked as being of “high” quality. While the other studies were still useful in addressing the research questions, the conclusions drawn in these studies are more at risk from potential bias. Notably, many studies were small in scale, lacked comparison groups and may have introduced biases through their sampling strategies (e.g. convenience sampling), which could limit the validity of the evidence they generated.

Finally, restrictions to English language-only texts very likely excluded potentially relevant articles, particularly from Latin America where social protection systems are widespread [44]).

## **5. CONCLUSION**

Social protection has been gaining visibility within the international policy discourse as a tool for preventing and alleviating poverty and reducing social and economic inequalities. Recognizing the overrepresentation of persons with disabilities amongst the economically and socially marginalized, international frameworks and national programmes and policies are increasingly advocating for greater inclusion of persons with disabilities in social protection. Given this directive, this systematic review sought to compile and evaluate existing evidence on access to and impact of social protection for persons with disabilities in low- and middle-income countries. In doing so, this review began to explore whether programmes are adequately disability-inclusive and, if not, then what are some of the means through which to improve access and impact for this target group.

Perhaps the most notable finding of this review is that there is a dearth of high quality, robust evidence which comprehensively evaluates these central questions.

To better guide policy and programmatic decisions, further research in the following areas is urgently needed.

Firstly, more research utilizing comparison groups drawn from the general population is needed in order to determine equity in access and impact. Among included studies in this review, only one assessed the difference in impacts and none compared access between beneficiaries with and without disabilities. Such an analysis is needed to assess whether persons with disabilities are accessing and capturing the same benefits from participation as other eligible persons without disabilities. As social protection seeks to improve social and economic equality, unequal access and lower impact from participation may propagate the continued marginalization and vulnerability experienced by many persons with disabilities.

Secondly, as persons with disabilities are not a homogeneous group, understanding how access and impact are modified by compounding factors such as gender, age and impairment types would be useful for gaining a more nuanced view on how the influences of these elements can promote or hinder participation among persons with disabilities.

Thirdly, as most of the studies on impact focused on a relatively limited subset of the intended functions of social protection – namely, protection of minimum living standards – broader assessments would help elucidate the effects of participation across the full spectrum of social protection's intended outcomes.

Fourthly, as most of the included studies focused on targeted social assistance in South Africa, more research covering a diverse array of types of social protection – particularly mainstream schemes – in a variety of locations would add greater breadth to the evidence base. As what works well in one situation may not transfer well to another, widening the evidence base to include a more diverse mix of programmes and contexts can be more informative for identifying common barriers as well as strategies with broad-based effectiveness.

Finally, in conducting further studies, emphasis should be placed on robust study designs and methods – with large, representative samples, appropriate comparison groups and controls for confounding. Among the quantitative included studies, all were cross-sectional and one was ecological, so other, more robust study designs

which present less of a risk of bias would be valuable. For qualitative studies, more transparent reporting of methods and representative sampling is needed.

Even though more research on this topic is urgently needed, the evidence emerging from this review indicates that access to social protection likely falls far below need, and that benefits from participation are mostly limited to maintaining minimum living standards and do not appear to hold the promise espoused in the social protection literature of long-term individual and societal social and economic development. A clear finding from the review is that in designing and implementing social protection programmes, a more nuanced approach is required to ensure they are appropriately disability-inclusive. Programmes need to improve their ability to both accurately assess disability as well as tailor interventions to address the specific needs of recipients with disabilities. Currently, there is broad recognition among policymakers of disability as a dimension of vulnerability and acknowledgment that persons with disabilities need to be considered whenever there is a concern with ensuring programmes truly address the needs of the most vulnerable. However, if dedicated attention is not given to the specific needs of persons with disabilities – or any other ‘vulnerable group’ – it is highly unlikely that actions taken will properly reflect their concerns or address their needs.



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## SECTION C. CASE STUDIES FROM VIETNAM AND NEPAL ON DISABILITY-INCLUSION IN SOCIAL PROTECTION



*Photo: Survey in progress in Nepal*

### Overview

*Section C draws on evidence from primary data collection conducted in the districts of Cam Le, Vietnam and Tanahun, Nepal. This research was funded by the Australian Government Department of Foreign Affairs and Trade under the research grant “Disability-Inclusive Social Protection in Asia & the Pacific” (grant number: 71687).*

This section draws on data collected in Cam Le, Vietnam and Tanahun, Nepal to explore in-depth the need for, access to and adequacy of social protection amongst people with disabilities.

Vietnam and Nepal were selected as country settings after a desk-based review of national social protection systems in Asia and the Pacific<sup>11</sup>, which was conducted by Matthew Walsham [1]. These countries were identified as having relatively strong social protection systems that had made concerted efforts to design programmes to address the needs of people with disabilities. The two districts of Tanahun and Cam Le were then chosen after consultations with in-country stakeholders, on the basis of having relatively well-functioning social protection administration and decent availability of disability-related services and supports compared to other districts across the country. Consequently, the findings from this research may not be representative of the situation across Vietnam or Nepal. However, these settings were chosen to allow the best opportunity to identify good practices in disability-inclusive social protection, which was the aim of the underlying funded research from which this thesis is drawn.

The main focus in each setting are the Disability Allowances, non-means-tested, non-conditional regular cash transfers, which also have other linked in-kind benefits (e.g. discounts on transportation, healthcare, educational scholarships). Other non-targeted forms of social assistance and insurance are also explored, although in less detail.

The underlying research project comprised three components in each country: (a) national-level policy analysis, (b) quantitative district-level data collection and, (c) qualitative district-level data collection. As highlighted in Chapter 3.4, the PhD candidate led on the design, implementation of data collection, analysis and write-up for all elements related to the quantitative data collection (component b). For components a & c, data collection and analysis were led by Matthew Walsham at LSHTM and in-country partners at HUPH and VaRG. The PhD candidate was responsible for the final analysis and write-up of those findings, including the finalisation of themes as written in the attached papers.

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<sup>11</sup> This research funding stipulated the geographic area of focus as Asia and the Pacific.

*Chapter 6 (Paper 3)* assesses need for social protection amongst people with disabilities in Cam Le, Vietnam and Tanahun, Nepal. Then, *Chapter 7 (Papers 4 & 5)* evaluates access of people with disabilities to available targeted- and non-targeted programmes in each setting. Finally, *Chapter 8* explores the adequacy of social protection amongst people with disabilities.

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## ***Chapter 6. Need for social protection amongst people with disabilities in Tanahun, Nepal and Cam Le, Vietnam***

### **Preamble**

The systematic review in *Chapter 4, Paper 1* found strong evidence that people with disabilities face a heightened risk of economic poverty compared to people without disabilities. More research in this area is still warranted as not all countries were represented in the review and consistent monitoring of poverty trends is critical for tracking progress on the SDGs. Further, the review only captured economic forms of poverty. Multidimensional measures, which directly assess deprivation in areas such as sustainable livelihoods and access to basic services, may better capture poverty and well-being [1]. Finally, very few included studies incorporated disability-related extra costs when considering poverty experienced by people with disabilities. The omission of these costs can substantially underestimate poverty amongst people with disabilities [2, 3].

Consequently, *Paper 3* compares poverty between people with and without disabilities in Cam Le, Vietnam and Tanahun, Nepal using both monetary and multidimensional poverty measures, which are based on SDG indicators. Extra costs of disability are also estimated using the Standard of Living approach [2]. These measures can assess need for social protection in line with its stated goals, particularly as outlined in the UN Special Rapporteur on the rights of persons with disabilities report on disability-inclusive social protection [4]. For example, social protection is intended to guarantee basic income security (protect against monetary poverty), as well as promote access to services, develop stronger livelihoods and achieve full and effective participation of people with disabilities in society (reduce multidimensional poverty) [4].

The findings from these analyses illustrate the need for social protection amongst people with disabilities in each context by evaluating the prevalence of different forms of poverty, as well as inequalities in comparison to people without disabilities. This paper also explores extra costs of disability and predictors of poverty amongst people with disabilities.

*Paper 3* combines quantitative data from Tanahun, Nepal and Cam Le, Vietnam. This paper has been submitted to *Oxford Development Studies* and is currently undergoing peer review. Supplemental materials can be found in Appendix 8 of this thesis.

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## Paper 3: Does disability increase the risk of poverty “in all its forms”?

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## RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

### SECTION A – Student Details

Student	Lena Morgon Banks
Principal Supervisor	Prof Hannah Kuper
Thesis Title	Investigating disability-inclusion in social protection programmes in low and middle income countries, with case studies from Vietnam and Nepal

*If the Research Paper has previously been published please complete Section B, if not please move to Section C*

### SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Oxford Development Studies
Please list the paper's authors in the intended authorship order.	Lena Morgon Banks, Monica Pinilla-Roncancio, Matthew Walsham, Shailes Neupane, Saurav Neupane, Yogendra Pradhananga, Karl Blanchet, Hannah Kuper
Stage of publication	Submitted

### SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Led on conceptualisation (development of methods, e.g. creation of questionnaires), data collection, analysis. Wrote the full original draft, which was reviewed by the other co-authors. Responsible for submitting to the journal.
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Student Signature: \_\_\_\_\_

Date: Mar 28, 2019

Supervisor Signature: \_\_\_\_\_

Date: Mar 28, 2019

**Does disability increase the risk of poverty “in all its forms”? Comparing monetary and multidimensional poverty between people with and without disabilities in Cam Le, Vietnam and Tanahun, Nepal**

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## **Abstract**

Ending poverty “in all its forms” is central to the fulfilment of the 2030 Sustainable Development Goals. To achieve this aim, it is critical to monitor progress towards poverty alleviation amongst groups at risk of exclusion, such as people with disabilities. Consequently, this research evaluates and compares poverty levels amongst people with and without disabilities in the districts of Cam Le, Vietnam and Tanahun, Nepal. The research used population-based surveys (n=12,397) and nested-case control studies (n=667) and applied both monetary and multidimensional indicators of poverty. Overall, people with disabilities experienced high levels of monetary and multidimensional poverty. People with disabilities also faced high disability-related extra costs, which substantially lowered their standard of living compared to people without disabilities. Inequalities between people with and without disabilities, as well as substantial disability-related extra costs, indicate that targeted policy responses are required to ensure people with disabilities can benefit from poverty alleviation interventions.

## **Introduction**

Disability and poverty are intimately linked, with the one reinforcing the other [1-3]. People living in poverty may face a heightened risk of disability, stemming, for example, from exposure to unsafe working and living conditions, malnutrition and poor access to healthcare, clean water, sanitation and hygiene. In turn, disability may lead to or exacerbate poverty through exclusion from work and education, as well as high spending on healthcare and other disability support services.

The international community is increasingly recognising the importance of including considerations of disability in poverty reduction strategies, most notably in the 2030 Sustainable Development Agenda [3, 4]. Importantly, monitoring plans are needed to ensure that progress towards poverty alleviation is being shared equally between people with and without disabilities [5]. For example, the 2030 Sustainable Development Goals (SDGs), which have been adopted by 193 countries, call for the disaggregation of all targets and indicators by disability so as to “leave no one behind” from advances towards eliminating poverty (SDG 1) and other Goals [4, 6].

However, poverty is a complex concept to define, and consequently there is no consensus on a single best measurement approach [7]. In its broadest definition, poverty can be described as “a state in which individuals or households show significant deficits in well-being” [8]. However, historically, monetary measures – such as income or expenditures – have been used to assess poverty [9, 10]. Often, an individual or household’s income is compared against an absolute threshold or “poverty line”, below which they are classified as living in poverty [9]. In many countries, poverty lines are calculated based on the minimum income deemed necessary to satisfy basic needs, such as food, shelter and other necessities [11]. In addition to national poverty lines, the World Bank’s international poverty line of \$1.90 per person per day (with 2011 purchasing power parity) is used to define and track “extreme poverty” across countries [12]. Poverty may also be measured relatively, by comparing an individual or household’s income or expenditures against what is typically commanded by others in that setting [9]. The diversity of poverty measurements is highlighted in the range of targets and indicators used to track progress towards the SDGs, particularly SDG 1, which seeks to “[e]nd poverty in all its forms” [13]. For example, the international poverty line and national poverty lines are the focus of SDG indicators 1.1.1 and 1.2.1, respectively, while relative monetary poverty is captured in SDG indicator 10.2.1 [13, 14].

While monetary measures are critical for assessing poverty, it is increasingly recognised that these indicators alone do not encompass all forms of deprivation and that poverty should be seen in multidimensional terms [15, 16]. For example, the capability approach advanced by Sen recognises that while income and other financial resources are helpful and often necessary, they are insufficient as holistic measures of well-being [17]. The ability to convert these resources into desired “capabilities” and “functionings”, such as being healthy, nourished, employed or having access to healthcare, education and other essential services, is the critical factor for maximising well-being and this varies significantly between individuals and contexts [18]. Directly measuring deprivation in these areas may better capture poverty and well-being than using monetary indicators alone. Consequently, Multidimensional Poverty Indexes (MPIs), using the Alkire-Foster method, have been used by many governments, as well as the United Nations Development Programme (UNDP), to collate and analyse data on a range of multidimensional indicators of

poverty [19, 20]. MPIs are used frequently in monitoring SDG indicator 1.2.2, which addresses “poverty in all its dimensions according to national definitions” [13].

People with disabilities may face an increased risk of poverty across both monetary and multidimensional measures. Studies have found people with disabilities face high levels of absolute monetary poverty using national or international poverty lines [21-23], as well as relative poverty compared to others without disabilities in their setting [24, 25]. Additionally, several studies have used MPIs to assess poverty among people with disabilities, with all finding a link between disability and multidimensional poverty [15, 21, 26, 27]. However, there are key concerns with the existing literature addressing this association. First, prevailing approaches may underestimate poverty and deprivation levels amongst people with disabilities. Notably, people with disabilities and their households frequently contend with additional disability-related expenses (e.g. personal assistance, additional medical or transportation costs, assistive devices) [23, 28-30]. Diverting resources towards these costs can lower standard of living for a given level of income, relative to other households without members with disabilities who do not incur these costs [26]. Households with members with disabilities will therefore often require a higher income threshold to meet basic needs. As such, there is growing support for adjusting poverty lines to capture these extra disability-related costs [23, 28]. Further, both monetary and multidimensional poverty measures most frequently use the household as the primary unit of analysis, which may mask intra-household inequalities [31]. For example, some studies have found people with disabilities are more likely to be malnourished or less likely to attend school compared to other household members [32-34]. These differences potentially indicate either a lower prioritisation in the division of household resources or additional barriers to meeting an adequate standard of living.

Understanding in greater depth the experience of both monetary and multidimensional poverty among people with disabilities is important for informing policy responses. For example, social protection programmes are increasingly being adopted in LMICs as a set of strategies for integrated poverty reduction, with many targeted explicitly to people with disabilities [35, 36]. More information on the lived experience of people with disabilities, however, is essential to better tailor

programmes to meet the needs of people with disabilities, who constitute 15% of the global population [37]. Consequently, this study aimed to compare levels of and contributors to monetary and multidimensional poverty amongst people with and without disabilities and their households in the districts of Cam Le, Vietnam and Tanahun, Nepal. These districts have both implemented programmes that seek to address poverty amongst people with disabilities.

## **Methods**

### ***Sampling and data collection procedures***

The districts of Tanahun in Nepal and Cam Le in Vietnam served as the study sites for this research. Tanahun is part of Province No. 4 in the Hills region of Nepal and is predominantly rural, while Cam Le is an urban district of the province of Da Nang in the South Central Coast region of Vietnam. These countries and districts were selected through a rapid policy review [38] and interviews with in-country stakeholders, with the objective of selecting areas that have begun to put in place programmes to target poverty amongst people with disabilities (e.g. disability-targeted cash transfers).

In both settings, data was collected through a population-based survey in each district, with a nested case-control study. Data collection was undertaken between May-June 2016 in Cam Le, Vietnam and August-October 2016 in Tanahun, Nepal.

A two-stage sampling strategy was undertaken for the population-based survey, in line with established methods [39-41]. Each setting had a sample size for the population-based survey of 6,000 people ages five and over, based on an anticipated prevalence of disability of 5% and 80% response rate. For the first stage, population-proportionate-to-size sampling was used to select clusters (30 in Tanahun, 75 in Cam Le), using the most recent national census as the sampling frame. A cluster was the smallest administrative unit (ward within a Village Development Committee (VDC) in Nepal, Population Group in Vietnam). For the second stage, compact segment sampling was employed to enumerate a set number of individuals within each cluster (200 for Tanahun, 80 for Cam Le).

The population-based survey measured disability amongst people ages five and over. However, for the purposes of this analysis, the sample is restricted to people

ages 15 and older to allow for better comparability across poverty measures (e.g. income, education). In Vietnam, the Washington Group Short Set was used to categorise people as disabled and to assess severity, while in Nepal, an accepted adaptation of the Washington Group Extended Set and the UNICEF/Washington Questions module on Child Functioning for children were used [25, 26]. These question sets have been validated in a range of contexts, including in LMICs, and have been recommended by the United Nations and other stakeholders for providing robust and comparable estimates of disability [28]. These tools focus on the level of difficulty (none, some, a lot or cannot do) an individual faces performing everyday activities (e.g. seeing, walking). For this study, disability was defined using cut-offs recommended by Washington Group protocol [42, 43], which are as follows:

- Nepal:
  - Reported “a lot of difficulty” or “cannot do” in at least one of the following domains: seeing, hearing, walking/climbing, communicating (understanding/being understood), remembering/concentrating, self-care, upper body strength, fine dexterity.
  - Reported experiencing symptoms of anxiety or depression “daily”, at a level described as “a lot”
- Vietnam
  - Reported “a lot of difficulty” or “cannot do” in at least one of the following domains: seeing, hearing, walking/climbing, communicating, remembering/concentrating, self-care.

Any person identified during the population-based survey as having a disability was invited to participate in the case-control study. Each case with a disability was matched to a person without a disability (control), who was of the same sex, resided in the same cluster and was of similar age (+/- 5 years) as the case. Only one control per household was permitted and control households could not include any household members with disabilities.

Trained data collectors used computer tablets to administer questionnaires, which had been translated into the local language (Nepali/Vietnamese). Questionnaire forms were created using Open Data Kit (ODK) to allow for mobile entry. The household questionnaire contained information on household membership (age, sex

of all members, disability screen for members 5+ years) and household-level socioeconomic status (e.g. income, assets, housing characteristics). The case control questionnaire explored in greater depth individual-level indicators of poverty, such as educational attainment, health, work status and social participation.

Ethical approval for this research was granted from the Ethics Committees at the [name removed for peer review], the Nepal Health Research Council and the [name removed for peer review]. All study participants gave informed written consent before the start of each interview.

### ***Measuring monetary poverty***

The following measures were calculated to assess economic poverty, in line with SDG indicators:

- 1) Poverty headcount, using the international poverty line of \$1.90 per person per day, with 2011 purchasing power parity (PPP) (SDG Indicator 1.1.1) and poverty gap.
- 2) Poverty headcount, using national poverty lines (SDG Indicator 1.2.1) and poverty gap.
- 3) Proportion of people living below 50% of median income (SDG Indicator 10.2.1)

All of the above measures used income data. Household heads reported average total household monthly income from all sources (including salary, remittances, gifts, social assistance transfers). Household income was equivalised for size and composition using the OECD equivalence scale [44].

The poverty headcounts were then calculated as the proportion of households whose per capita income fell below the national or international poverty line, with the latter adjusted for PPP using 2011 conversion factors [45]. The national poverty line in Vietnam is VND 780,000 per person per month (equivalent to \$3.82 per person per day with 2011 PPP) [46], while the poverty line in Nepal is NPR 19,261 per person per year (equivalent to \$2.14 per person per day with 2011 PPP) [47, 48]. Additionally, the poverty gap amongst the poor (i.e. those below the poverty line) was calculated as the average distance of poor households' income from each of the poverty lines, expressed as a proportion of that poverty line [49].



### ***Accounting for extra costs of disability***

Extra costs of disability were calculated using the Standard of Living approach described by Zaidi & Burchardt, which has been used in other studies for this purpose, including in LMICs [28, 50]. This approach measures how much income is required to raise disabled households to the same standard of living as a nondisabled household. The underlying rationale for this approach is that disabled households allocate money towards disability-associated expenses (e.g. extra transportation, caregiving, medical expenses), so that, for a given level of income, these households have fewer resources available to contribute towards improving their living standards compared to households without members with disabilities. This relationship is explained through the model:

$$S = \alpha \ln(Y) + \beta D + \gamma X + \epsilon$$

where  $S$  is an indicator of standard of living,  $Y$  is household income,  $D$  is disability status and  $X$  is other explanatory characteristics for standard of living (e.g. rural/urban status, household age structure) and  $\epsilon$  is the intercept term. Extra costs of disability are calculated as the quotient of the coefficients for the disability and income variables ( $-\beta/\alpha$ ).

Several models were trialled to estimate the extra costs (see Supplementary File 1 [Appendix 8] for further details). The final model was selected based on goodness-of-fit and after testing variables for multicollinearity. Included variables, based on the above equation, were as follows:

- $S$  – standard of living index quintiles, derived from the principal component analysis of asset ownership and housing characteristics
- $\ln(Y)$  - Natural logarithm of total household income from all sources was not equivalised for household size, in accordance with recommendations [23, 50, 51]
- $D$  - Disability status as per previously mentioned definition
- $X$  – Other explanatory variables (in Nepal: household's location (rural/urban), total number of members, number of adults aged 65 and over and children under 16; in Vietnam: household size, location (wards),

proportion of dependents, at least one member has a college degree, no adult males in household)

Ordered logit regressions were used to model extra costs of disability in each setting and the resulting estimated costs was used to construct adjusted monetary poverty lines (international and national) for households with members with disabilities.

### ***Measuring multidimensional poverty***

The Alkire-Foster (AF) Method has been widely used for designing and computing MPIs that are relevant to different contexts and study purposes [16, 52]. Under this approach, an MPI uses a set of dimensions and linked indicators in areas considered critical to the experience of poverty.

The AF Method uses a double cut-off approach to assess poverty. First, deprivation cut-offs are set for each indicator. The sum across all indicators in the MPI falls between 0 and 1, with 1 reflecting complete deprivation across all indicators and 0 indicating no deprivation in any indicator. Each indicator also has an assigned weight, which reflects its relative contribution to poverty. Next, the individual's weighted sum of deprivations is calculated and compared against a final cut-off  $k$  – “the multidimensional poverty line” – to determine if an individual is considered multidimensionally poor. Choice of indicators and dimensions, their weights and cut-offs, as well as the overall poverty cut-off  $k$  are subject to normative judgements and assumptions, such as on what are acceptable levels of deprivation and how important each indicator is to an individual's experience of poverty. To improve the validity of these choices, participatory and expert-based approaches are recommended [14]. Further, robustness testing – particularly in the rank ordering (i.e. comparison of poverty levels between groups or areas) with different MPI structures and values of  $k$  – is also important for strengthening the utility of the MPI in informing policy decisions [53].

Three indices are calculated when using the AF Method. First, the poverty headcount (H), or prevalence of poverty, indicates the proportion of individuals in a population who are considered multidimensionally poor. Second, the average deprivation share or intensity (A) provides an indication of the depth of poverty by calculating the average weighted proportion of deprivations that the poor experience

(i.e. those below the poverty threshold). Finally, the adjusted headcount or MPI, which is the product of H and A, presents a summary measure of both the breadth and depth of multidimensional poverty. In addition to these three measures, the percentage contribution of each indicator to the MPI provides information about the composition of poverty. Percentage contributions are calculated as the product of each indicator's censored headcount ratios (proportion of the population who is both multidimensionally poor and deprived in that indicator) and the indicator's weight, divided by the MPI.

The MPI used in this study included five dimensions (livelihoods, social inclusion, access to services, health and well-being and household living conditions) and 13 indicators (Table 1). These dimensions and indicators are relevant for people across the lifecycle (ages 15+) and for people with and without disabilities. The selection of dimensions and indicators was based on a review of the literature of existing MPIs, including ones used in other studies exploring multidimensional poverty amongst people with disabilities [15, 22, 54]. In addition, the selected indicators and dimensions are grounded within international [28, 48] and national [49] strategies for poverty alleviation, including the SDGs and United Nations Convention on the Rights of Persons with Disabilities. For example, food security, access to services and adequate living conditions are indicators of an individual and their household's ability to meet basic needs, while indicators in work and health are important for developing stronger and more resilient livelihoods that can protect against persistent poverty. Additionally, indicators in social inclusion relate to agency and participation, which have been highlighted as importance in the experience of poverty, particularly amongst people with disabilities [55-57].

For the thirteen indicators, seven are specific to individuals (livelihoods, voting, decision-making, individual access to water and sanitation, violence and health events) and the remainder (living conditions, spending on healthcare and food insecurity) are measured at the household-level. For each indicator, deprivation cut-offs are based primarily on international or national standards (see notes in Supplemental Table 1 [Appendix 8]). The MPI uses nested weights, in which dimensions are all given equal weighting, which is then subdivided amongst indicators in that dimension [58]. As such, each dimension is considered equally

important in the experience of poverty, as is each indicator within a poverty dimension. The poverty cut-off, or the level at which an individual was identified as multidimensionally poor, was equal to 30% ( $k=0.30$ ) – meaning she/he is deprived in 30% or more of the weighted sum of indicators (equivalent to the weight of more than one dimension).

**Table 1. Multidimensional poverty dimensions, indicators and weights**

<i>Dimension</i>	<i>Indicator</i>	<i>Deprived if...</i>	<i>Weight</i>
Livelihoods	Work & old age security	Individual (age 15-64) has not worked in the last 12 months and is not currently attending school; OR Individual (65+) is not working and does not receive a pension/age-based cash transfer	10%
	Food security	Household faces food insecurity	10%
Social inclusion	Voting	Individual did not his/her vote in the last election	10%
	Decision-making	Individual not consulted in family decision-making	10%
Access to services	Access to improved sanitation	Individual faces difficulties accessing improved sanitation facility	6.67%
	Access to clean water	Individual faces difficulties accessing safe drinking water	6.67%
	Healthcare	Household spent more than 25% of their monthly income on healthcare in the previous 30 days	6.67%
Health and well-being	Health event	Individual experienced a serious health problem in the last 12 months	10%
	Violence	Individual experienced discrimination, physical or verbal abuse in the last 12 months	10%
Living conditions	Cooking fuel	Household cooks with dung, wood or charcoal	5%
	Floor material	Household has dirt, sand or dung floor	5%
	Overcrowding	Household has 3+ people per room used for sleeping	5%
	Asset ownership	Household does not own more than one of the following assets (radio, TV, telephone, bike, motorbike, refrigerator, air conditioner, computer), and does not own a car	5%

## **Data analysis**

Multivariate regression was used to compare indicators of monetary and multidimensional poverty between people with and without disabilities, and amongst people with disabilities. Regression analyses included adjustments for the individual's age and gender and the household's location (rural/urban for Nepal, ward number for Vietnam). Age of onset (before/after age 18) and disability severity were included in regression models that were restricted to people with disabilities only. Disability severity was calculated as the sum of scores across Washington Group questions (0=no difficulty, 1=some difficulty, 2=a lot of difficulty, 3=cannot do; anxiety/depression=3), divided by the maximum score for the question set. All p-values presented are from adjusted analyses, unless indicated otherwise.

## **Results**

Overall, 5,692 people were screened for disability in Nepal (response rate: 94.9%) and 6,705 people in Vietnam (response rate: 95.1%). In Nepal, 214 people were identified as having a disability (prevalence: 3.8%, 95%CI: 3.3-4.3%), of whom 199 were ages 15 or older. In Cam Le (Vietnam), 150 people were identified as having a disability (prevalence: 2.5%, 95% CI: 2.1-2.9%), of whom 138 were ages 15 or older. In both settings, disability prevalence increased significantly with age ( $p<0.001$ ) and in Nepal disability was slightly more prevalent in men after adjusting for age (4.5% vs 3.2%,  $p=0.04$ ) [59].

All 138 people with disabilities aged 15 and older in Vietnam (100%) and 194 of 199 people with disabilities in Nepal (97%) agreed to take part in the case-control study, and were matched to controls without disabilities (total response rates: 98.0% and 97.7% for Vietnam and Nepal, respectively). Although matching was imperfect when the sample was restricted to the subset of people aged 15+, cases and controls in this group were still similar on key characteristics (Table 2).

**Table 2: Characteristics of study sample, case-control (ages 15+)**

	<b>Tanahun, Nepal</b>		<b>Cam Le, Vietnam</b>	
	<i>Cases (n=194)</i>	<i>Controls (n=193)</i>	<i>Cases (n=138)</i>	<i>Controls (n=139)</i>
<i>Gender</i>				
Male	103 (55.4%)	107 (53.1%)	65 (47.1%)	71 (51.1%)
Female	91 (46.9%)	86 (44.6%)	73 (52.9%)	68 (48.9%)
<i>Age group</i>				
15-35	40 (20.6%)	37 (19.2%)	28 (20.3%)	29 (20.9%)
36-64	91 (46.9%)	92 (47.7%)	57 (41.3%)	60 (43.2%)
65+	63 (32.5%)	64 (33.2%)	53 (38.4%)	50 (36.0%)
<i>Location</i>				
Urban	47 (24.2%)	45 (23.3%)	138 (100%)	138 (100%)
Rural	147 (75.8%)	148 (76.7%)	n/a	n/a
<i>Household size (SE)</i>	4.6 (0.14)	4.4 (0.16)	4.9 (0.16)	4.7 (0.16)
<i>Disability severity score<sup>a</sup> (SE)</i>	0.24(0.01)***	0.02 (0.003)	0.31(0.02)***	0.04 (0.005)

\*\*\* p<0.001, bivariate analysis comparing cases and controls; SE=standard error

### **Disability and monetary poverty**

Few people in either study setting were living in extreme poverty (3.3% in Vietnam and 6.3% in Nepal, amongst all households), according to the international poverty line of \$1.90 per person per day (2011 PPP) (Table 3). Still, people with disabilities were approximately twice as likely to be living in households below this line, although the difference was only significant in Nepal. The poverty gap was similar between poor disabled and non-disabled households in Nepal, although surprisingly, the poverty gap was slightly greater amongst poor, non-disabled households in Cam Le, Vietnam.

Disabled households were also significantly more likely to living in poverty using national poverty lines compared to non-disabled households in both Vietnam (16.8% vs 5.8%, p=0.003) and Nepal (11.1% vs 6.6%, p=0.05). Amongst the poor, however, there was no significant difference in the intensity of poverty in either setting. Further, disabled households faced high relative poverty compared to the median income of others in each setting: in Nepal, 35.4% of disabled households had incomes less than 50% of the median (compared to 22.8% of non-disabled households, p<0.001), while in Vietnam, 38.7% of disabled households were 50% below the median (compared to 14.5% of non-disabled households, p<0.001).

**Table 3. Monetary poverty between households with and without members with disabilities**

	Tanahun, Nepal		Cam Le, Vietnam	
	Disability (n=198)	No disability (n=1,265)	Disability (n=137)	No disability (n=1,328)
<i>International poverty line (\$1.90 per person per day, 2011 PPP)</i>				
Poverty headcount (n, % population)	21 (10.6%)*	71 (5.6%)	9 (6.6%)	39 (2.9%)
Poverty gap (average % shortfall)	24.8%	29.3%	33.8%*	61.5%
Adjusted poverty headcount (n, % population) <sup>a</sup>	31 (15.7%)*	71 (5.6%)	19 (13.9%)*	39 (2.9%)
Adjusted poverty gap (average % shortfall)	41.7%**	29.3%	62.1%	61.5%
<i>National poverty lines<sup>Q</sup></i>				
Poverty headcount (% population)	22 (11.1%)*	83 (6.6%)	23 (16.8%)*	77 (5.8%)
Poverty gap (average % shortfall)	31.8%	32.6%	39.3%	54.2%
Adjusted poverty headcount (% population) <sup>b</sup>	36 (18.2%)*	83 (6.6%)	55 (40.2%)*	77 (5.8%)
Adjusted poverty gap (average % shortfall)	34.2%	32.6%	40.8%*	54.2%
<i>Relative poverty</i>				
Below 50% median income (% population)	70 (35.4%)*	288 (22.8%)	53 (38.7%)*	192 (14.5%)

<sup>Q</sup>National poverty line is VND 780,000 per person per month in Vietnam (equivalent to \$3.82 per person per day, PPP) and NPR 19,261 per person per year in Nepal (equivalent to \$2.14 per person per day, PPP).

<sup>a</sup>Adjusted international poverty line is equivalent to \$2.14 in Nepal and \$3.32 in Vietnam; <sup>b</sup> Adjusted national poverty lines are VND 1,363,000 per person per month (equivalent to about \$6.67 per person per day, PPP);

\*p<0.05, \*\*\* p<0.001.

Additionally, households with members with disabilities experienced high disability-related extra costs that lowered their standard of living for a given income. Several models were trialled to estimate disability-related extra costs, with all finding similar levels of extra costs. In the final model, extra costs were estimated to be 29.4% and 74.7% of household income in Nepal and Vietnam, respectively. Consequently, households were spending approximately 6000 NPR (\$243, 2011 PPP) in Nepal and 4.4 million VND (\$656, 2011 PPP) in Vietnam on disability-related costs per month. Raising the international poverty line by these amounts leads to an increase in the poverty headcount amongst disabled households from 10.6% to 15.7% in Nepal and from 6.6% to 13.9% in Vietnam. Similarly, adjusting national poverty lines by extra costs increased poverty headcounts from 11.1% to 18.2% in Nepal from 16.8% to 40.2% in Vietnam. This large increase in poverty in Vietnam indicates that many disabled households are living close to, but slightly above, the national poverty line. The intensity of poverty amongst disabled households also deepened slightly as a result of the adjusted poverty lines in both settings.

## Disability and multidimensional poverty

Turning to multidimensional measures of poverty, the prevalence of poverty was much higher amongst people with disabilities compared to people without disabilities in both settings (57.7% vs 25.9% in Nepal,  $p<0.001$ ; 45.7% vs 2.2% in Vietnam,  $p<0.001$ ) (Table 4). Amongst the poor, people with disabilities were deprived in about 40% of dimensions in each setting, which was significantly higher compared to people without disabilities in Nepal ( $p=0.002$ ), but not Vietnam. Consequently, the MPI amongst people with disabilities was more than double that of people without disabilities in Nepal (0.243 vs 0.096,  $p<0.001$ ) and 23-times higher in Vietnam (0.165 vs 0.007,  $p<0.001$ ). Robustness testing of different MPI structures and cut-offs of  $k$  consistently found people with disabilities had a higher MPI compared to people without disabilities, regardless of the formulae used to generate the indicators (see Supplementary File 2 [Appendix 8]).

**Table 4. Multidimensional poverty index between cases and controls (ages 15+)**

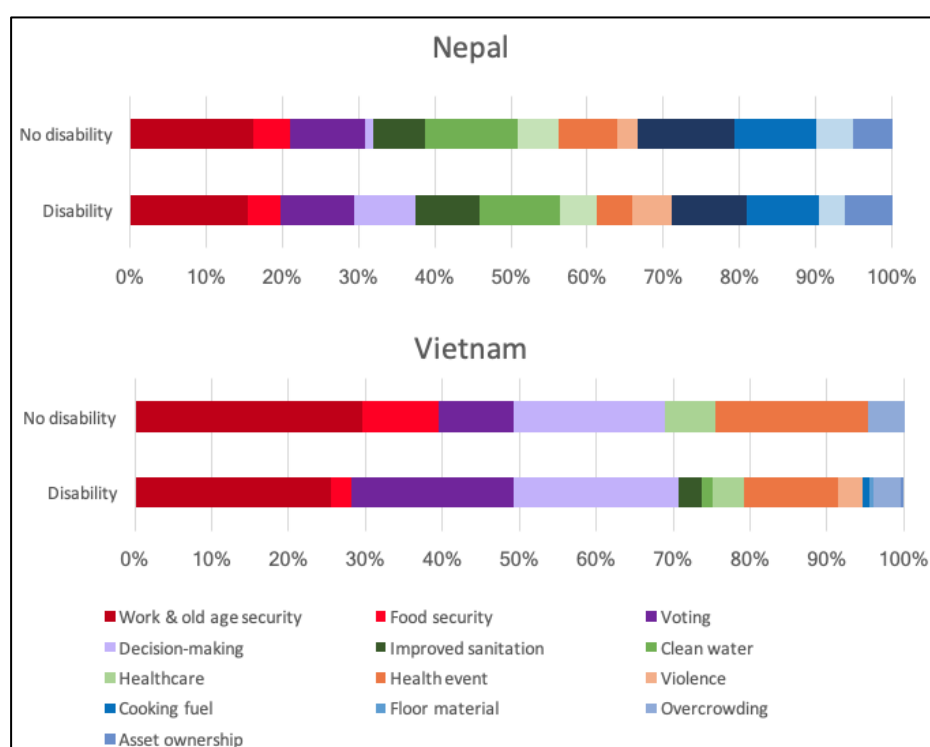
	Tanahun, Nepal		Cam Le, Vietnam	
	Disability (n=194)	No disability (n=193)	Disability (n=138)	No disability (n=139)
<b>MPI summary measures</b>				
Prevalence of poverty $H$ (n, % population)	112 (57.7%)***	50 (25.9%)	63 (45.7%)***	3 (2.2%)
Poverty Intensity $A$ (% weighted deprivations)	42.1%**	37.2%	36.1%	33.9%
MPI	0.243***	0.096	0.165***	0.007
<b>Deprivation by indicator (uncensored headcount), n (%)</b>				
Work	91 (46.9%)***	54 (28.0%)	91 (65.9%)***	52 (37.4%)
Food security	24 (12.4%)*	13 (6.7%)	9 (6.5%)	7 (5.0%)
Voting	53 (27.3%)**	30 (15.5%)	62 (44.9%)***	7 (5.0%)
Decision-making	40 (20.6%)***	3 (1.6%)	57 (41.3%)***	9 (6.5%)
Water	115 (59.3%)	105 (54.4%)	16 (11.6%)**	3 (2.2%)
Sanitation	75 (38.7%)*	55 (28.5%)	6 (4.4%)	1 (0.7%)
Healthcare spending	46 (23.7%)*	30 (15.5%)	29 (21.0%)*	19 (13.7%)
Health event	31 (16.0%)	24 (12.4%)	50 (36.2%)***	16 (11.5%)
Violence	27 (13.9%)***	6 (3.1%)	9 (6.5%)***	0 (0.0%)
Cooking fuel	158 (81.4%)	160 (82.9%)	8 (5.8%)	3 (2.2%)
Flooring	142 (73.2%)*	123 (63.7%)	3 (2.2%)	1 (0.7%)
Overcrowding	40 (20.6%)	37 (19.2%)	33 (23.9%)	33 (23.7%)
Assets	77 (39.7%)*	55 (28.5%)	3 (2.2%)	2 (1.5%)

Comparison between people with and without disabilities is statistical significance in multivariate analysis: \* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$



People with disabilities were twice as likely to be multidimensionally poor compared to people without disabilities due to large disparities on almost all MPI indicators compared to people without disabilities. This difference was significant for five of seven individual level indicators (work, voting, decision-making, sanitation and violence) and four of six household indicators (food security, health care spending, flooring and assets) in Nepal. In Vietnam, people with disabilities were significantly more likely to be deprived in six of seven individual indicators (all but sanitation) and only one household indicator (healthcare spending). Few households in Vietnam, with and without disabled members, were deprived on measures in the living conditions dimension.

Figure 1 illustrates the percentage contribution of each of the 13 indicators to the MPI in both districts. In Nepal, the indicators for work/old age security, cooking fuel, flooring, water and sanitation are major contributors to poverty for both people with and without disabilities. In contrast, the contribution of many of the indicators in the household living conditions and access to services dimensions are relatively small for both people with and without disabilities in Vietnam. Work/old age security and experiencing an adverse health event are the largest contributors for both people with and without disabilities. In both settings, violence and social inclusion indicators

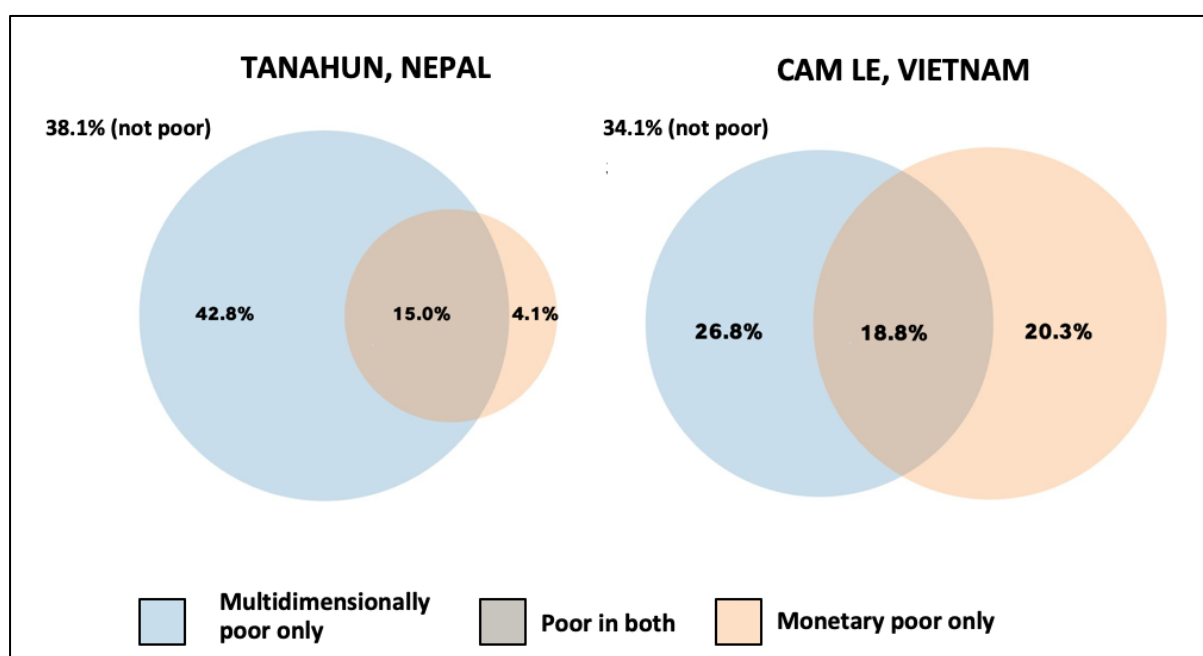


**Figure 1.** Percentage contribution to MPI by indicator and disability status

are much larger contributors to multidimensional poverty for people with disabilities compared to people without disabilities.

### Comparing income and multidimensional poverty

Amongst people with disabilities, 38.8% in Nepal and 34.1% in Vietnam were not poor by either monetary (using adjusted national poverty line) or multidimensional measures (Figure 2). In Nepal, 15.0% were poor by both measures, while 42.8% were only multidimensionally poor. Only a small proportion of people with disabilities in Nepal were monetary poor only (4.1%). In Vietnam, 18.8% were poor by both measures, while 20.3% were monetary poor only and 26.8% were multidimensionally poor only.



**Figure 2.** *Overlap between monetary (national poverty line) and multidimensional poverty headcounts, amongst people with disabilities*

Turning to predictors of poverty, people living in multidimensional poverty had higher disability severity scores in both Vietnam and Nepal (Table 5). Multidimensional poverty was also positively associated with having functional limitations affecting self-care and cognition in both settings, as well as communication in Vietnam. In Nepal, having a sensory impairment was negatively associated with multidimensional poverty. For monetary poverty, there was no association with disability severity or particular functional limitations in either setting. In Nepal, people living in urban areas were less likely to experience monetary poverty, while in Vietnam, receiving social assistance was weakly protective against monetary poverty.

People with disabilities who were not living in poverty by either measure had lower disability severity scores in both settings. Further, in Nepal, people with sensory limitations were more likely not to experience poverty, while in Vietnam, people with communication, cognitive and self-care limitations were less likely to be free of poverty.

**TABLE 5. Predictors of poverty amongst people with disabilities, age 15+**

	Tanahun, Nepal (n=194)			Cam Le, Vietnam (n=138)		
	None aOR (95% CI) <sup>a</sup>	Monetary aOR (95% CI) <sup>a</sup>	MPI aOR (95% CI) <sup>a</sup>	Not poor aOR (95% CI) <sup>a</sup>	Monetary aOR (95% CI) <sup>a</sup>	MPI aOR (95% CI) <sup>a</sup>
<i>Gender</i>						
Men	Reference	Reference	Reference	Reference	Reference	Reference
Women	0.7 (0.4, 1.3)	1.7 (0.8, 3.6)	1.6 (0.9, 2.9)	1.0 (0.5-2.1)	0.6 (0.3, 1.2)	1.2 (0.6, 2.3)
<i>Age group</i>						
15-35	Reference	Reference	Reference	Reference	Reference	Reference
36-64	1.4 (0.6, 3.2)	0.8 (0.3, 2.1)	0.7 (0.3, 1.5)	2.4 (0.9, 7.1)	0.8 (0.3, 1.9)	0.3 (0.1, 0.7)**
65+	1.7 (0.7, 4.1)	0.7 (0.3, 2.1)	0.5 (0.2, 1.1)	1.9 (0.6, 5.5)	0.6 (0.3, 1.7)	0.6 (0.2, 1.5)
<i>Location</i>						
Rural	Reference	Reference	Reference	n/a	n/a	n/a
Urban	1.5 (0.7, 2.9)	0.2 (0.1, 0.7)*	0.8 (0.4, 1.5)	n/a	n/a	n/a
<i>Age of onset</i>						
0-17 years	Reference	Reference	Reference	Reference	Reference	Reference
18+ years	0.9 (0.4, 1.7)	0.8 (0.4, 2.0)	1.4 (0.7, 2.7)	0.6 (0.3, 1.3)	1.7 (0.8, 3.7)	1.0 (0.5, 2.2)
<i>Functional limitation<sup>b</sup></i>						
Sensory	1.9 (1.0, 3.5)*	1.2 (0.6, 2.7)	0.5 (0.2, 0.8)*	1.3 (0.6, 2.9)	0.7 (0.3, 1.6)	0.7 (0.3, 1.7)
Physical	0.7 (0.4, 1.3)	0.9 (0.4, 1.9)	1.5 (0.8, 2.7)	1.5 (0.7, 3.4)	0.8 (0.4, 1.8)	1.0 (0.4, 2.1)
Communication	0.6 (0.3, 1.3)	1.1 (0.5, 2.5)	1.9 (0.9, 3.8)	0.2 (0.1, 0.6)**	0.9 (0.4, 2.1)	5.7 (2.4, 13.6)***
Cognitive	0.5 (0.2, 1.0)	0.5 (0.2, 1.3)	2.5 (1.2, 5.4)*	0.2 (0.1, 0.7)**	1.1 (0.5, 2.4)	3.8 (1.7, 8.2)**
Self-care	0.6 (0.3, 1.2)	0.9 (0.4, 2.0)	2.0 (1.0, 3.9)*	0.3 (0.1, 0.7)**	0.9 (0.4, 1.9)	3.6 (1.7, 7.8)***
Anxiety/depression	0.4 (0.1, 1.3)	1.2 (0.4, 4.3)	3.4 (0.9, 12.3)	n/a	n/a	n/a
Household receives social assistance	0.9 (0.4, 1.8)	1.9 (0.8, 4.6)	1.3 (0.7, 2.6)	1.1 (0.5, 2.2)	0.4 (0.2, 0.9)*	1.0 (0.5, 2.1)
<i>Severity score (Mean)</i>	0.20**	0.25	0.26***	0.24**	0.30	0.39***

<sup>a</sup> Adjusted by age, gender, and for Nepal, location

<sup>b</sup> Not mutually exclusive. Domains derived from Washington Group questions as follows: physical (difficulties walking, with upper body function or fine dexterity), sensory (hearing/seeing), communication, cognitive (remembering, learning and understanding).

Statistically significant in the multivariate analysis (controlling for age, gender, location): \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

## Discussion

This study found high levels of both monetary and multidimensional poverty amongst people with disabilities and their households compared to people without disabilities. Across almost all monetary and multidimensional poverty measures, people with disabilities were significantly poorer compared to people without disabilities.

Overall, 10.6% and 6.6% of households with members with disabilities were living in extreme poverty in Nepal and Vietnam respectively, and faced a shortfall in income equivalent to about a quarter to a third of the international poverty line. After factoring in the extra costs of disability, which were estimated to amount to 29.2% and 74.7% of household income in Nepal and Vietnam respectively, the extreme poverty headcount rose by 4.9% in Vietnam and 7.3% in Nepal. Similarly, the poverty headcount using national poverty lines rose by 7.1% in Nepal and 23.4% in Vietnam after adjusting for disability-related extra costs. The sharp increase in poverty amongst people with disabilities in Vietnam using the adjusted national poverty line indicates that many people with disabilities are living close to, but slightly above the poverty line.

While there is a growing body of research exploring the relationship between monetary poverty and disability [1, 21], few other studies have taken into account disability-related extra costs. Existing research is consistent with this study's finding that incorporating these costs significantly raises the proportion of people with disabilities living in poverty. For example, Braithwaite & Mont estimated extra costs of disability at 9% and 14% of household income in Vietnam and Bosnia and Herzegovina, respectively [23]. Including these disability-related expenses raised the prevalence of poverty among people with disabilities from 16.4% to 20.1% in Vietnam and 21.1% to 30.8% in Bosnia and Herzegovina. Similarly, in Cambodia, extra costs were estimated at 19% of household income, which nearly doubled poverty from 18% to 37% among households with members with disabilities [60]. Finally, in China disability-related extra costs were estimated using 2006 data to range from 8-43%, which raised the national poverty prevalence amongst all households (with and without disabled members) from 35.8% to 38.8% [61].

The value of extra costs of disability estimated in this study, particularly for Vietnam, are higher than those found in several other studies. Part of this difference may be explained by differences in the definition of disability used. For example, other estimates of extra costs from other areas of Vietnam range from 9-12% [23, 51, 62], compared to 74.7% in this study; however, these estimates include people with more mild levels of functional limitations (experiencing “some difficulty” in functioning using Washington Group questions). H. Van Minh et al found that when cut-offs similar to this study (“a lot of difficulty” or “cannot do”) were used, extra costs doubled to almost quadrupled in value [51].

Further, it is important to note that the Standard of Living approach to measuring extra costs of disability only captures what households are spending, not necessarily all expenses needed for full participation. Low extra costs measured through the Standard of Living approach may indicate that many needed expenses are beyond households’ means, or services/items are not available for purchase in certain areas [29, 30]. As Cam Le and Tanahun are relatively wealthy districts, with decent availability of disability-related services, households in these areas may have a higher capacity for purchasing disability-related services and items, leading to higher spending. Government subsidies for these items are also lacking in both settings, meaning out-of-pocket spending is required to access needed services: for example, in Vietnam, while health insurance coverage is high, plans do not cover the cost of assistive devices and most rehabilitation services [63]. These factors may also explain why measured extra costs were higher in Cam Le compared to Tanahun: people with disabilities in Cam Le have higher incomes and live in a more urban setting with better availability of disability-related compared to Tanahun. As such, people with disabilities in Cam Le have a higher capacity to spend on disability-related items compared to people with disabilities in Tanahun, leading to higher extra costs estimates under the Standard of Living approach. The actual value of all goods and services required for full participation may be similar in both contexts, but the Standard of Living Approach only captures actual spending. Further research is needed to identify unmet disability-related expenses and quantify their total cost to obtain comprehensive estimates of disability-related extra costs.

Despite these extra expenditures, people with disabilities experienced high levels of multidimensional poverty, indicating continued unmet inclusion needs. In Vietnam and Nepal, 45.7% and 57.7% of people with disabilities were multidimensionally poor, respectively, compared to 2.2% and 25.9% of people without disabilities. Multidimensionally poor people with disabilities also experienced a higher proportion of weighted deprivations compared to people without disabilities (in Vietnam: 36.1% vs 33.9%; in Nepal: 42.1% vs 37.2%), although this was statistically significant in Nepal only. Amongst individual MPI indicators, people with disabilities were more likely to be deprived compared to people without disabilities in areas related to social inclusion (voting, decision-making), violence, work and old age security, and healthcare spending in both contexts, inequalities which are reinforced in other studies [22, 64-68]. Increasingly, social exclusion, discrimination and low levels of participation are considered consistent dimensions of poverty amongst people with disabilities [57]. The high levels of multidimensional poverty, particularly among people with disabilities, in comparison to monetary poverty also illustrates the limitations of using income as a proxy for all forms of well-being [17]. Directly measuring deprivation in areas such as social inclusion, access to services, health and living conditions may better capture actual well-being, as well as provide a more nuanced understanding of the lived experience of poverty.

Other studies, using different MPI structures, have similarly found high levels of multidimensional poverty amongst people with disabilities, and significant differences in comparison to people without disabilities [15, 21, 22, 27, 69]. As with this study, inequalities between people with and without disabilities on individual indicators (e.g. social inclusion, health, employment) and in overall MPI measures tend to be more apparent when measured at the individual-level compared to the household-level. For example, Pinilla-Roncancio & Alkire found disabled households were more likely to be multidimensionally poor compared to non-disabled households in only 4 of 11 LMICs when using the UNDP Global MPI, in which all indicators are measured at the household-level [69]. In contrast, inclusion of individual-level indicators (e.g. employment status, health status, educational attainment) in other MPIs in other settings has evinced starker and more consistent differences between people with and without disabilities [15, 21, 22, 27]. These gaps highlight intra-household

inequalities and the importance of individual-level measurements of poverty, particularly amongst people with disabilities.

Levels and contributors to multidimensional poverty differed between Vietnam and Nepal, reflecting differences in development between the two settings. Vietnam is a middle-income country, and Cam Le, is an urban and relatively wealthy district, while Nepal is a low-income country and Tanahun is predominantly rural and poor [70]. Consequently, most households with and without disabilities in Cam Le, Vietnam had met most basic needs (e.g. adequate housing conditions, minimum asset levels, improved sanitation and water sources, cooking fuel), while in Tanahun, Nepal, many households still do not have these needs fulfilled. As such, multidimensional poverty levels were lower in Vietnam than Nepal. However, inequalities between people with and without disabilities were higher in Vietnam, which may reflect the theory that as countries develop, people with disabilities are more likely to be excluded from progress [2].

The overlap between monetary and multidimensional poverty also differed in Nepal and Vietnam. In Nepal, almost all people with disabilities who were monetary poor (using the extra costs adjusted national poverty line) were also multidimensionally poor. However, many more people with disabilities experienced multidimensional poverty without monetary poverty, indicating that income is not a sufficient proxy for capturing all forms of well-being amongst people with disabilities. In Vietnam, in contrast, while there was some overlap between the two measures, a large proportion of people with disabilities were only multidimensionally poor or only monetary poor. This finding may reflect the high spending on disability-related extra costs in Vietnam, which, although impoverishing, reduces multidimensional poverty among some, but not all, individuals. Alternatively, other dynamics, such as discrimination and negative attitudes, may lead to multidimensional poverty among people with disabilities, even if their households are not facing monetary poor. More research is needed to understand what factors or interventions are successful at reducing multidimensional poverty among people with disabilities who are still monetary poor, as well as what helps people with disabilities escape both multidimensional and monetary poverty.



Several factors affected individuals' likelihood of experiencing either monetary or multidimensional poverty. Rural residence in Nepal was a positive predictor, in line with global trends, including for research amongst people with disabilities [71, 72]. Disability severity was also strongly associated with worsening multidimensional poverty, which mirrors findings from a multi-country study from Ethiopia, Malawi, Uganda and Tanzania [22]. Further, functional limitations affecting self-care, cognition and, in Vietnam, communication, were positively associated with multidimensional poverty. Monetary poverty, in contrast, was not significantly associated with disability severity or particular functional limitations; other factors not explored in this study, such as whether the person with a disability is engaged in paid work and the quality of that work, or caregiving responsibilities of other household members, may better explain monetary poverty amongst people with disabilities. Finally, while this study did not find that female gender was significantly linked to either multidimensional or monetary poverty amongst people with disabilities, other studies from other regions have highlighted the additional disadvantage from gender biases, particularly for multidimensional poverty [15, 22]. The lack of positive association with gender may reflect cultural norms in the study settings; alternatively, disadvantage due to gender may not have been fully captured in the selected MPI indicators or the degree of difference was insufficiently large for the study's power.

Interestingly, receipt of social assistance did little to protect individuals against poverty. In Vietnam, social assistance was weakly protective against monetary poverty, but not multidimensional poverty, and had no effect on either forms of poverty in Nepal. This finding illustrates that social protection may not be sufficient to ensure people with disabilities and their households are protected from poverty. Further research is needed to explore how these and other poverty-reduction programmes could be improved in order to reduce both monetary and multidimensional forms of poverty amongst recipients with disabilities.

Several limitations should be considered when interpreting this study's findings. First, households were the main unit of analysis for all monetary poverty measures and some indicators within the MPI, which assumes deprivations or resources are shared equally among all individuals. This assumption is questionable, particularly for

people with disabilities, who may face discrimination within the household or additional barriers to participation (e.g. physical inaccessibility of WASH facilities). For example, for monetary poverty, people with disabilities may not be involved in financial decision-making within the household, or not receive an equal share of available resources. Further, although the MPI indicators were created to reflect individual-level deprivations as much as possible, some indicators – such as food security and living conditions – are measured at the household-level and may thus mask individual deprivations. For example, studies have found children with disabilities are more likely to be malnourished compared to their siblings without disabilities [34], and so measuring food security at the household-level may not capture an individual's access to food and nutrition. Similarly, people with disabilities may not be able to use some household assets (e.g. phones, televisions, cars) if these do not have accessibility features. Second, differences in quality may be an issue for certain indicators in the MPI. For example, people with disabilities are often more likely to engage in less stable, lower paid work compared to people without disabilities [73], which is not captured in this study's indicator for employment. Third, participatory approaches could strengthen the validity of the MPI, so as to ensure that the resulting structure is in line with how people with and without disabilities conceptualise poverty in both study settings. Finally, both settings have relatively well-functioning social protection system, decent availability of disability supports and are wealthier than other areas of the country. Consequently, levels of poverty may be higher in poorer areas of Nepal and Vietnam, while inequalities between people with and without disabilities may be exacerbated in areas without disability-related services and supports and less effective social protection administration. Exploring how and why poverty levels and inequalities differ in other districts is important for further research and informing policy decisions. For example, research in Vietnam found that the poverty gap between people with and without disabilities was attenuated in districts with better health care and infrastructure [74].

## **Conclusion**

People with disabilities and their households experienced high levels of monetary and multidimensional poverty, as well as significant inequalities compared to people without disabilities. These findings carry implications for the design and

implementation of policy responses to ensure the mandate “no one left behind” from poverty alleviation is fulfilled. Both Vietnam and Nepal have put in place social protection and other poverty-reduction programmes to address poverty among its citizens, including people with disabilities. However, as is, available policies and programmes appear insufficient to protect people with disabilities and their families from poverty. Increasing access to available programme, as well as strengthening their design and delivery, may be required to reduce poverty and inequality. Policy responses may include increasing access to disability-related services and supports, while reducing the financial burden of out-of-pocket expenditures on these items. Further, complementary efforts are needed to combat discrimination and social exclusion of people with disabilities.

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## ***Chapter 7. Access to social protection schemes amongst people with disabilities in Tanahun, Nepal and Cam Le, Vietnam***

### **Preamble**

The systematic review on disability and social protection (*Chapter 5, Paper 2*) found little evidence was available assessing access of people with disabilities to available social protection programmes. Further, six of the eight studies on access included in the systematic review were of access to the Disability Grant in South Africa and only two studies explored inclusion in mainstream schemes. Few considered factors that increased access to social protection amongst people with disabilities (e.g. by gender, age) or no study compared participation between people with and without disabilities, which could provide a measure of equity in access. Consequently, more research is needed from other contexts, from mainstream as well as disability-targeted schemes and that explores predictors of access.

To contribute to the evidence gap, *Papers 4 and 5* explore access of people with disabilities to available social protection schemes in Cam Le, Vietnam and Tanahun, Nepal, respectively. Each country has a disability-targeted, non-means-tested, unconditional cash transfer, with other in-kind linked benefits (e.g. discounts on transportation, healthcare) and services (e.g. vocational training). Both countries also offer a range of non-disability targeted social assistance schemes and some forms of social insurance. These papers measure participation of people with disabilities in these different schemes, compare enrolment between people with and without disabilities and explore predictors of participation amongst people with disabilities. Measures of access use data from population-based surveys with disability measured using the Washington Group questions [1-5].<sup>12</sup> Qualitative research, which was led by co-authors with contributions from the PhD student, explore factors affecting access to social protection amongst people with disabilities.

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<sup>12</sup> The Washington Group Short Set was used in Vietnam [5]. The Washington Group Extended Set 3 *Short Set Enhanced* [1] and Child Functioning Module Ages 5-17 (Basic Function domains) [4] were used in Nepal



*Paper 4* has been published the *International Social Security Review* and *Paper 5* has been accepted for publication in the *European Journal of Development Research*. Both papers underwent peer-review.

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## Paper 4: Access to social protection among people with disabilities: Evidence from Vietnam

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Student	Lena Morgon Banks
Principal Supervisor	Prof Hannah Kuper
Thesis Title	Investigating disability-inclusion in social protection programmes in low and middle income countries, with case studies from Vietnam and Nepal

*If the Research Paper has previously been published please complete Section B, if not please move to Section C*

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Where was the work published?	International Social Security Review		
When was the work published?	January 2019		
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Date: Mar 12, 2019

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Date: 26/3/19

## **Access to social protection among people with disabilities: Evidence from Vietnam**

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## **Abstract**

Although people with disabilities are frequently targeted as key beneficiaries of social protection, little is known on their access to existing programmes. This study uses mixed-methods to explore participation in disability-targeted and non-targeted social protection programmes in Vietnam, particularly the district of Cam Le. Coverage of social assistance and health insurance among people with disabilities was 53% and 96% respectively. However, few accessed employment-linked social insurance and other disability-targeted benefits (e.g. vocational training, transportation discounts). Factors affecting access included accessibility of the application process, disability assessment procedures, awareness and perceived utility of programmes, and attitudes on disability and social protection.

## **Introduction**

Social protection is increasingly used by governments in low- and middle-income countries as a strategy for ensuring individuals and their households are protected from poverty and other forms of vulnerability across the life cycle [1]. More broadly, aims of social protection include promoting the development of stronger livelihoods, ensuring access to healthcare and other social services, fostering economic and social development, and reducing inequalities [2, 3]. Social protection may encompass a range of policies and programmes, including contributory schemes (social insurance), as well as non-contributory, tax-financed schemes [3]. The latter includes various forms of social assistance, in which beneficiaries receive transfers in cash or kind.

Nationally appropriate “social protection floors” for all – in which States provide their citizens with a set of guarantees such as basic income security and access to healthcare and other essential services – have been advanced by the International Labour Organization’s Social Protection Floor Recommendation (2012) and recognised in the 2015-2030 Sustainable Development Goals (SDGs) as critical for inclusive and sustainable growth and development [4]. While social protection floors should be available for all, coverage is particularly important for individuals or groups who face a higher risk of poverty and other forms of marginalization [2, 5].

There are an estimated one billion people living with disabilities. As a group, people with disabilities are frequently targeted as key beneficiaries in national and international social protection strategies and programmes because they are significantly more likely to be living in poverty and face a wide range of social, economic and cultural forms of exclusion [6-8]. In addition to a needs-based argument for including people with disabilities in social protection programmes, the right to inclusion in all aspects of society – including in social protection – on an equal basis with others is well-established in international treaties such as the Universal Declaration of Human Rights (Article 22 and 25) and the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (Article 28) [9, 10].

To fulfil the right to inclusion in social protection, states must ensure equitable access for people with disabilities to mainstream social protection programmes – such as health insurance, social security and other benefits where disability is not an explicit condition of eligibility [11]. Additionally, targeted programmes may be needed to address disability-specific concerns, such as access to assistive devices, specialist health and educational services. Account also must be made for the higher costs incurred by people with disabilities in participating in society, as a result of needs for accessible transport, carers, assistive devices and so on [3, 11, 12]. According to recent estimates from the International Labour Organization, 27.8% of people with severe disabilities globally receive some form of disability benefit [3]. However, there is considerable regional variation, with coverage lowest in Asia and the Pacific at 9.4% and highest in Eastern Europe (97.9%) [3]. These estimates also result from extrapolation of the 15% global estimate of disability prevalence to each country's population, rather than direct surveys. Additionally, little is known about inclusion of people with disabilities in mainstream schemes not specifically targeting people with disabilities, or about barriers to accessing either mainstream or targeted social protection [13].

Consequently, this study seeks to explore access to social protection among people with disabilities, using Vietnam as the study setting. In addition to quantitative measures of access, this paper also identifies challenges and facilitators to participation in social protection.

## Overview of Social Protection Entitlements in Vietnam

The right to social security is codified in Article 34 of the recently amended Constitution of Vietnam (2013) [14]. Resolution 70/NQ-CP/2012 further describes the State's strategy for strengthening social protection between 2012-2020 [15]. Overall, there are four main components to Vietnam's social protection framework: (1) social assistance to groups deemed at high risk of poverty; (2) social insurance to mitigate financial risks associated with sickness, occupational injuries and from ageing; (3) programmes promoting access to basic services, such as education, healthcare and clean water/sanitation; and (4) policies to improve opportunities for decent work [15].

Within this remit, Vietnam has a range of social protection policies and programmes in place. Non-contributory entitlements include a number of disability-targeted schemes, as well as programmes targeted to other groups deemed to be at high risk of poverty. For contributory schemes, various forms of insurance are mandatory for most formal sector employees, with optional opt-in schemes available to the rest of the workforce.

### ***Disability-targeted social protection entitlements***

People with disabilities in Vietnam are eligible for the disability-targeted entitlements listed in Table 1. In order to be eligible for these entitlements, people with disabilities must first undergo an assessment of disability. Most assessments are conducted by the Disability Degree Determination Council (DDDC), which is located within the commune-level People's Committee, one of the most decentralized administrative units in Vietnam [16]. The DDDC determines both the type and degree of disability using the Joint-Circular 37/2012/TTLT-BLĐTBXH-BYT-BTC-BGDĐT,<sup>13</sup> which has two assessment tools (for children under six and people over six). The degree of disability ("mild", "severe" or "extremely severe") determines which social protection benefits a person is eligible for. Degree determinations are calculated using a standardized scoring system based on the applicant's ability to perform eight daily life activities (walking, eating and drinking, toilet hygiene, personal hygiene, dressing, hearing and understanding what people say, communicating using speech, and participating in housework like folding clothes, sweeping, washing dishes and

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<sup>13</sup> Hereafter, Joint Circular 37

cooking), with or without assistance from others. Assessments are based on in-person observations of functioning as well as interviews with the applicant and/or their caregiver.

If the DDDC cannot reach a decision on the degree of disability, or if the applicant wishes to appeal their conclusion, the applicant is referred to the Medical Examination Council (MEC) [16]. MECs are located in provincial capitals and in Hanoi. In contrast to the DDDC, which uses a functioning-based approach, the MEC evaluates disability degree using solely medical criteria. Disability degree is based on the proportion of bodily injury due to disability, with 81% and above considered “extremely severe” and 61-80% considered “severe” [17].

**Table 1. Disability-targeted social protection provisions**

Entitlement	Social Protection Component	Eligibility (disability degree)	Description of entitlement
Social assistance	Social assistance to groups at high risk of poverty	Severe, extremely severe	<i>Unconditional minimum monthly cash transfer</i> : 405,000 VND [US\$18] (severe), 540,000 VND [US\$24] (extremely severe). Slightly higher amounts for children and older adults. A separate cash transfer is available for caregivers of people with extremely severe disabilities (VND 405,000/month [US\$18])
Health insurance	Social insurance, access to basic services	Severe, extremely severe	State pays full premium for health insurance; coverage of 95% of eligible medical expenses
Education supports	Access to basic services	Any classification	Various (e.g. individual education plan, adapted admission criteria; exempted tuition fees/scholarship if also poor)
Vocational training & employment supports	Opportunities for decent work	Any classification	Various (e.g. free vocational training at recognised centres, preferential loans for self-employed, incentives for employers to hire people with disabilities)
Transportation discounts	Access to basic services	Any classification	Free or subsidized public transportation.

Some entitlements, namely subsidised health insurance and social assistance, are reserved for people with the highest degree of disability (“severe”, “extremely

severe”), while others are open to people with disabilities of any degree classification (e.g. transportation discounts, free vocational training). It is important to note that Table 1 outlines the minimum requirements as codified in national laws and policies. Provinces have leeway in how to implement policies, including in increasing the value of the Disability Allowance, expanding eligibility or in offering additional programmes.

Finally, veterans of the Resistance war against the United States (the Vietnam war) who developed a disability during their service or have family members who become disabled due to exposure to Agent Orange are entitled to separate social assistance programmes. These schemes offer a much higher level of support, ranging from VND 1,479,000-3,609,000 (US\$65-159) per month [18]. Eligibility criteria is determined by the MEC, based on a defined list of diseases, impairments or abnormalities. Documentation of these conditions can be certified at district- or higher-level hospitals and forwarded to the MEC.

### ***Non-disability targeted social protection entitlements***

People with disabilities may also be eligible for programmes aimed at other targeted groups, if they meet their eligibility criteria. For example, unconditional social assistance is available to older adults (aged 80+ with no other sources of income), orphans, single parents, and people living with HIV in poverty [19]. Amounts range from VND 270,000 to 675,000 per month (US\$12-30) [19]. However, an individual who is eligible for more than one form of social assistance can only receive one form of support, the one of the highest amount. The only types of social assistance that can be received concurrently with other schemes are the Single Parents’ Allowance and the Caregivers of People with Extremely Severe Disabilities Allowance.

While people with “severe” and “extremely severe” disability degrees are one target group for State-subsidised compulsory health insurance (CHI), other social assistance recipients, as well as children under six, students, organ donors, workers in certain industries and individuals living under or near the poverty line are also eligible. Under CHI, the state covers a portion of the premium as well as user fees for eligible medical expenses. Premium subsidies range from 100% for children under 6 to 30% for students [20, 21]. CHI covers 80% of medical expenses, but for certain users (i.e. people with severe disabilities, people below the poverty line,



children under six), the State provides a further subsidy to cover user fees (95%-100%) [19, 22]. Coverage in CHI may also be through formal sector employment, where enrolment is mandatory for workers who have a contract of at least 3 months. In this case, the premium is set to 6% of the employee's monthly salary, of which the employer contributes 4.5% and the employee 1.5% [21, 23]. For individuals not covered by State- or employer- subsidised CHI, voluntary health insurance (VHI) is available for purchase, with premiums equivalent to 4.5% of monthly salary with no employer contribution. For both VHI and employer-subsidised CHI, 80% of eligible health expenses are covered by plans.

Finally, social insurance regimes are available through either compulsory social insurance (CSI) or voluntary social insurance (VSI). CSI – which is mandatory for formal sector employees with at least a one-month contract – covers sickness, maternity, labour accidents and occupational disease, retirement and survivor allowances [34]. CSI contributions are set at 26% of the employee's monthly salary, of which employers contribute 18%. In contrast, anyone can opt into VSI, which covers only retirement and survivor allowances, and requires a monthly contribution by the employee of 22% of their self-declared income [34].

## **Methods**

A mixed-methods approach was used to evaluate the extent to which people with disabilities are accessing existing social protection programmes, including barriers and facilitators to access. First, a national policy analysis was conducted to provide an overview of available social protection entitlements, and how their design and implementation may affect access for people with disabilities. Second, qualitative and quantitative research was conducted in one district of Vietnam to measure coverage and uptake of specific entitlements and explore factors influencing access in greater depth. While the focus was predominantly on disability-targeted entitlements, access to non-targeted schemes was also assessed where feasible.

Ethical approval for this research was granted from the Ethics Committees at the London School of Hygiene & Tropical Medicine and the Hanoi University of Public Health. Informed written consent was obtained from all study participants before beginning any interviews. For children below 18 years (age of consent) and people

with impairments that severely limited their ability to understand/communicate, a carer answered on their behalf as a proxy.

All data was collected between May-December 2016.

## **Setting**

Vietnam was selected as the study site for this research as it was identified in a rapid policy analysis as having a strong social protection system that has made concerted efforts to be inclusive of people with disabilities. As such, it presented a good opportunity to describe examples of good practice in the design and delivery of disability-inclusive social protection.

While the policy analysis was national in scope, district level data collection was used to explore access to social protection among people with disabilities in practice. Cam Le, part of the province of Da Nang in Central Vietnam, was selected as the study district after consultations with stakeholders. During these consultations, Cam Le was highlighted as an area with a well-functioning social protection administration and a strong network of Disabled People's Organisations (DPOs) and disability-support services. Cam Le's disability-targeted social protection entitlements also go above the national minimum. Specifically, CHI coverage is expanded to children under 17 with "mild" disability degree classifications and Disability Allowance allotment are topped up for the poor and older adults with a disability, if they receive monthly social assistance of less than 500,000 VND. As such, using Cam Le as the setting for district-level data collection meant that potential strengths of the system in terms of disability-inclusion could be identified.

## **National policy analysis**

A national policy analysis was conducted in order to describe the overall social protection landscape in Vietnam, including the strengths and challenges associated with ensuring access to social protection for people with disabilities. Data was compiled through three avenues: (1) a literature review, (2) in-depth interviews with key stakeholders and (3) a consultative workshop. For the literature review, relevant legal frameworks, policies and programmes in Vietnam as well as existing research on the issue were identified through a scoping review of academic and grey literature in both English and Vietnamese. To complement the literature review, in-depth

interviews were conducted with sixteen key stakeholders within relevant government ministries, United Nations agencies, non-governmental organisations (NGOs), and Disabled Peoples' Organizations (DPOs). Participants were identified based on a review of existing projects and programmes related to disability and/or social protection. Interviews explored the design and delivery of social protection particularly for disability-targeted entitlements, factors influencing access for people with disabilities, strengths and challenges of programmes and priorities for reform. Findings were analysed thematically. Finally, a consultative workshop of over 50 stakeholders working in disability and social protection across Vietnam was held in May 2016 to further explore challenges and facilitators to access.

### **Quantitative research in Cam Le**

Quantitative data collection was comprised of a population-based survey of disability across Cam Le, with a nested case-control study to compare knowledge of and participation in social protection between people with and without disabilities.

For the population based survey, the 2009 national census was used as the sampling frame [24]. A two-stage sampling strategy was employed based on a methodology used in other surveys [25]. In the first stage, probability-proportionate-to-size sampling was used to select 75 clusters in Cam Le. Clusters were "Population Groups", the lowest administrative unit in Vietnam (average size: 162 people). In the second stage, compact segment sampling was used to select households within clusters. With this method, maps of each selected cluster were divided with the assistance of village leaders or staff at nearby health centres into equal segments of approximately 80 people. One segment was then randomly selected, and households were visited systematically beginning from a random start point, until the sum of members aged 5+ across households reached 80 people. A minimum sample size of 3,000 people was needed to measure the prevalence of disability (with expected prevalence of disability = 5%, precision required = 20%, design effect = 1.5, response rate = 90% and confidence = 95%). However, the sample was increased to 6,000 to account for uncertainty in the expected disability prevalence estimate and to ensure adequate numbers for the case control.

Within the population-based household survey, household heads reported on the functioning of all household members aged 5 years and older, using the Washington Group Short Set Questionnaire [26]. The Washington Group Short Set comprises six questions on an individual's ability to perform everyday activities (seeing, hearing, walking, remembering/concentrating, self-care and communicating). Respondents select one of four possible response options on level of difficulty in performing each activity: "none", "some", "a lot" or "cannot do". People who were reported to experience "a lot of difficulty" or "cannot do at all" for at least one question were considered to have a disability. This cut-off is in line with international guidelines. It is also closely aligned with the eligibility criteria for disability-targeted social protection, particularly social assistance, as outlined in Joint-Circular 37. In addition to measuring disability, the household survey also included questions on household socio-economic status and participation in social protection programmes.

Any individual who was identified during the household survey as having a disability was invited to take part in a case-control study. The case-control questionnaire explored in greater depth knowledge of and participation in various social protection programmes, amongst other indicators. In addition to recruitment through the population-based household survey, 72 people with disabilities who were participating in disability-targeted schemes were selected as additional cases from registers of the Disability Allowance; selection was based on proximity to included clusters (i.e. within the same ward/commune). Each case (whether identified from the survey or the register) was matched to a control without a disability (according to the Washington Group Short Set), who was of the same gender and area of residence, and similar in age ( $\pm 5$  years). Controls could not be from households with members with disabilities.

All questionnaires were administered in Vietnamese by trained data collectors using computer tablets. Data was analysed using STATA 15. Among people recruited through the population-based survey, multivariate regression was used to compare participation in various schemes between respondents with and without disabilities, controlling for age and gender.

## **Qualitative research in Cam Le**

In-depth, semi-structured interviews were carried out with people with disabilities who were and were not benefiting from social protection (namely disability-targeted programmes), as well as district- and community-level stakeholders. Interviews with people with disabilities focused on their knowledge of disability-targeted programmes and their experience of accessing relevant schemes. Key informant interviews centred on understanding the ways in which the planning and implementation of social protection programmes facilitates or impedes access for people with disabilities.

A purposive sample of 32 participants with disabilities were identified, using data collected through the population-based survey, selected to reflect variation in terms of impairment type, sex, age (children, working-age and older adults) and geographic distribution. A total of 19 provincial-, district- and community-level stakeholders were selected through snowball sampling, comprising disability service providers, representatives of DPOs, and decision makers/administrators responsible for social protection and related services. Interviews with all participants were transcribed in Vietnamese and a thematic approach was used to analyse findings.

## **Findings**

### **Description of the study samples**

In a population-based survey of over 6,705 household members were selected and 6,379 screened for disabilities (response rate: 95.1%). Overall, 150 individuals were identified as having a disability (prevalence: 2.5%, 95% CI<sup>14</sup>: 2.1-2.9%). Prevalence of disability did not differ by gender (Men: 2.3%, 95% CI: 1.8-2.9%, Women: 2.6%, 95% CI: 2.1-3.2%), but increased substantially with age (from 1.1% in children 5-18, to 13.2% in adults 76+,  $p < 0.001$ ). In total, 444 people took part in the case-control study (150 people with disabilities recruited from the population based study, 72 Disability Allowance recipients recruited from registers and 222 age-sex-cluster matched controls without disabilities). The response rate was high (98%), with only eight controls refusing to participate. Cases and controls were well matched by age

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<sup>14</sup> CI = confidence interval. CI measures the probability that a population parameter will fall between two set values.

and gender, as there were no significant differences in these characteristics between groups.

For the qualitative research, 32 people with disabilities were included (response rate=100%). Of 32 people, 24 were interviewed directly and for eight participants, information was gathered through their caregivers (for people with disabilities under 18 and one adult with severe physical and communication impairments). Twenty respondents were receiving the Disability Allowance. By impairment type, the following breakdown was observed: physical/mobility (n=17), communication (n=10), vision (n=5), hearing (n=5), psychosocial (n=5), intellectual/cognitive (n=5); 14 respondents had multiple impairments. Respondents ranged in age from 5-84 years old (5-17 years: n=7, 18-64 years: n=19, 65+ years: n=5) and there was a near equal mix by gender (female, n=18).

### **Social protection access**

Over half (52.7%) of all people with disabilities identified in the survey were recipients of some type of social assistance, which was significantly higher than for people without disabilities (11.7%) (Table 2). The Disability Allowance was the predominant source of social assistance accessed among people with disabilities (71% of recipients of social assistance). Overall, coverage of the Disability Allowance was 40%, with no participants accessing the scheme who did not meet the study's definition of disability. There were no statistically significant differences by sex across any social protection programme.

Coverage of health insurance was universally high for both people with and without disabilities, although people with disabilities were slightly more likely to be recipients. Among people with disabilities, health insurance was primarily CHI, due to disability or other reasons (e.g. recipient of another type of social assistance).

In the survey group, no one with a disability was accessing social insurance, due in large part to exclusion from the labour market, particularly the formal sector. In contrast, approximately a fifth of people without disabilities reported enrolment in social insurance, higher than among people with disabilities, yet still indicating low coverage among workers of retirement pensions and protection against risks such as workplace injury.

**Table 2. Social protection enrolment among people with and without disabilities in Cam Le district.**

	People with disabilities (n=150)	People without disabilities (n=222)	aOR (95% CI)
<b><i>Social assistance</i></b>			
Any social assistance	82 (52.7%)	26 (11.7%)	9.6 (5.6-16.5)***
Disability Allowance	60 (40.0%)	0 (0 %)	n/a
Old Age Allowance (among adults, aged 80+; or 60+ and below the poverty line)	12 (35.3%) <sup>a</sup>	12 (35.3%) <sup>a</sup>	0.8 (0.2-2.5)
Other social assistance	15 (10.0%)	15 (6.8%)	1.4 (0.7-3.1)
<b><i>Health insurance</i></b>			
Any health insurance	144 (96.0%)	196 (88.3%)	2.9 (1.1-7.2)*
State-subsidised health insurance	109 (72.7%)	60 (27.0%)	7.7 (4.7-12.5)***
<b><i>Social insurance</i></b>			
Social insurance (among people who worked in the last year)	0 (0%)	24 (21.2%)	n/a

Note: aOR: adjusted odds ratio (adjusted for age and sex); Statistically significant: \*p≤0.05, \*\*p≤0.01, \*\*\*p≤0.001;

<sup>a</sup>Includes two individuals between age 60-79 who were not below the poverty line based on household income.

As outlined in Table 1, disability-targeted benefits other than the Disability Allowance and health insurance are available to all disability degree classifications. In the population-based survey, only one person had received a mild classification. Along with the 132 Disability Allowance recipients (60 population-based sample, 72 recruited from registers), uptake of these other benefits was very low (Table 3).

**Table 3. Uptake of entitlements among recipients of disability-targeted social protection in Cam Le district (n=135)**

Disability-targeted entitlement	Aware (%)	Uptake <sup>Ω</sup> (%)
Transportation discounts	6 (4.5%)	2 (1.5%)
Educational discounts (among children under 18) <sup>a</sup>	5 (23.8%)	2 (8.3%)
Livelihoods supports (vocational training, preferential loans), among people 15-65 <sup>b</sup>	19 (14.2%)	17 (17.1%)
Allowance for caregivers	14 (10.6%)	12 (8.9%)

<sup>Ω</sup>Among people aware of entitlement

<sup>a</sup> n=24

<sup>b</sup> n=99

In comparing characteristics of people with disabilities who were and were not receiving disability-targeted social protection, coverage decreased with increasing

age (89% for children under 18 to 21% for adults over 75). Coverage was highest for people with communication difficulties and lowest for people with sensory impairments. It is important to note that 92% of people with communication difficulties had multiple functional limitations (compared to 51% of people with disabilities overall). There was no difference between recipients and non-recipients by severity of disability.

**Table 4: Characteristics of Disability Allowance recipients compared to non-recipients with disabilities**

	<b>Receiving Allowance (n=132)<sup>a</sup></b>	<b>Not receiving Allowance (n=78)</b>	
	<b>n (%)</b>	<b>n (%)</b>	<b>aOR (95% CI)</b>
Female	70 (58.3%)	50 (60.8%)	1.0 (0.6-1.9)
Age group			
- 5-18 years	23 (85.2%)	4 (14.8%)	Reference
- 19-40 years	48 (76.2%)	15 (23.8%)	0.6 (0.2-1.9)
- 41-60 years	35 (61.4%)	22 (38.6%)	0.3 (0.08-0.9)*
- 61-75 years	19 (46.3%)	22 (53.7%)	0.2 (0.04-0.5)**
- 76+ years	7 (20.6%)	27 (79.4%)	0.05 (0.01-0.2)***
Functional limitation <sup>d</sup>			
- Mobility	61 (52.6%)	55 (47.4%)	1.3 (0.6-1.8)
- Sensory (visual/hearing)	23 (45.1%)	28 (54.9%)	1.1 (0.6-1.9)
- Remembering	62 (70.5%)	26 (29.6%)	1.7 (0.9-3.2)
- Self-care	43 (54.4%)	36 (45.6%)	1.0 (0.5-1.9)
- Communication	53 (73.6%)	19 (26.4%)	2.0 (1.0-4.0)*
- Multiple	69 (61.1%)	44 (38.9%)	1.2 (0.6-2.2)
	<b>Mean</b>	<b>Mean</b>	<b>Coefficient (95% CI)<sup>b</sup></b>
Severity score	5.4	5.6	0.5 (-0.4 – 1.4)

Note: aOR: adjusted odds ratio (adjusted for age and sex); Statistically significant: \*p≤0.05, \*\*p≤0.01, \*\*\*p≤0.001; <sup>a</sup> Includes people recruited from Disability Allowance registers; <sup>b</sup> Adjusted for age, sex; <sup>c</sup> Severity score: Total across six Washington Group domains (0=no difficulty, 1=some, 2=a lot, 3=cannot do for each domain); maximum score is 18; <sup>d</sup> Not mutually exclusive (i.e. sum >100%)



## **Factors influencing access to social protection among people with disabilities**

From both the national policy analysis and research in Cam Le, several factors emerged which affected access to social protection among people with disabilities. These factors concerned: (1) geographic accessibility, (2) financial accessibility, (3) disability assessment criteria and procedures, (4) awareness and perceived utility of programmes, (5) broader disability-inclusive planning, and (6) attitudes on disability and need for social protection.

While the focus was predominantly on disability-targeted schemes – as they were by far the most known and accessed by people with disabilities – many challenges and facilitators are applicable to non-targeted schemes.

### ***Geographic accessibility***

In Vietnam, applications for all forms of social protection are conducted at the local commune-level People's Committees, one of the lowest administrative units. Prior to the introduction of Decree No. 28/2012/ND-CP in 2012, applications for disability-targeted programmes were conducted at the provincial capital. The shift in application location was widely cited by key informants at the national and local level as improving coverage of disability-targeted programmes.

*“Now [the disability assessment] moves to the People's Committee because the People's Committee is the closest to people in the community, which avoids missing cases. Before the Council was at provincial-level and there were so many severely disabled in the province, they could not cover them all, they could not meet all the people with disabilities.”* (Key informant)

*“The empowerment of the commune authority is one of its advantages. Commune authorities are more active in identifying people with disabilities. They are also closer to the targeted group who need to be identified...[As] the [DDDC] needs to directly meet the person to identify the form and level of disabilities, it is much easier and more accessible for a person to visit the commune hall compared with visiting [provincial] city hall.”* (Key informant)

Additionally, local officials noted that home visits were offered for applicants with severe functional limitations who were unable to travel to assessment locations, which they felt improved access.

However, not all people receive their assessment of disability at the local level. When the DDDC cannot make a determination on an assessment, cases must then be referred to the Medical Evaluation Council (MEC), which is located at provincial level. Children under six and people with mental health conditions were noted to be particularly likely to be referred to the MEC. Additionally, if an applicant contests the results of their assessment, they can appeal the decision, but re-evaluations are done by the MEC. While over 80% of disability-targeted social protection recipients in the quantitative survey completed their application at the commune-level and reported little issue with getting to application points, the remainder of recipients as well as key informants noted that travel to the provincial capital presented challenges to access. These barriers could be prohibitive, particularly for people with mobility limitations or who live in remote areas without adequate transportation links.

### ***Financial accessibility***

Direct application costs are low (VND 50,000, about US\$2). For appeals, however, applicants must cover the assessment fee by the MEC if their contestation is not supported. As the appeal assessment fee is high (VND 1,150,000, about US\$50), key informants noted that while this fee may protect against excessive contestations, it disproportionately impacts poorer applicants.

Additionally, indirect and opportunity costs of making the appeal could also be high, particularly for cases requiring re-evaluation at the MEC. While the assessment fee is waived for DDDC referrals and successful appeals, travel to the provincial centre and associated costs (e.g. accommodation, food) are not. Furthermore, applicants and anyone accompanying them must forgo time spent on other activities, such as work or school.

### ***Disability assessment criteria and procedures***

In 2012 the assessment criteria for determining eligibility, and importantly, 'disability degree' classifications were updated through Joint-Circular 37. With the implementation of this policy tool, assessments changed from a system based

primarily on medical classification of impairments to one focusing more on functioning. For example, as part of the disability degree classification under Joint Circular 37, the DDDC assesses whether a person can walk independently, with some help or not at all, based on self-reporting or in-person observation. In contrast, the MEC would diagnose a musculoskeletal impairment, and then consult Circular 20/2014/TT-BYT, which has a list of percentage “bodily injury” for a range of impairment types and health conditions. The main assessment body also switched from the MEC, which is comprised of medical professionals, to the DDDC, which is comprised of a range of representatives from different local government bodies, as well as DPO members where possible.

These changes to disability assessment procedures have been credited by key informants with greatly expanding access to social protection, which is reflected in national enrolment figures. In 2009, fewer than 385,000 people with severe disabilities nationally were receiving the Disability Allowance, but by 2014, that had doubled to more than 700,000 recipients.

The use of a tool that does not require medical expertise greatly expands the capacity of the State to conduct assessments, particularly in areas of the country where medical resources are in short supply. Further, new procedures and policies are now more in line with the UNCRPD. For example, the involvement of DPOs promotes participation of people with disabilities in the implementation of social protection. Additionally, the move towards more functioning-based assessment criteria is closer to definitions of disability promoted in the UNCRPD.

Still, the policy review and key informants noted several limitations to the disability assessment criteria and procedures. Criteria focus disproportionately on physical functioning and self-care, and tend to underestimate the impact of certain impairments, notably profound hearing and communication impairments as well as mental health conditions. Key informants involved in assessments noted this could lead to lower degree classifications, or exclusion altogether:

*“Deaf people receive nothing from social welfare because they can walk, eat, have a bath, etc. without help. They can do all of this. Some cannot speak but*

*it is not enough for receiving social welfare. So, they are excluded.”* (Key informant)

Additionally, providing assessments to children under six using Joint Circular 37 was reported as a persistent challenge. Consequently, most young children are referred to the MEC, which as mentioned previously creates additional barriers to access, as well as delays the receipt of needed support at a critical age.

There are also concerns that DDDC assessors are inadequately trained to conduct assessments, leading to inconsistent implementation and outcomes between communes and districts. Further, while, the DDDC is supposed to include the head of the commune-level DPO, in practice very few communes have a legal DPO. For example, the capital of Hanoi has 584 commune-level administrative units but by 2013 it had only 63 commune-level DPOs [27].

### ***Awareness and perceived utility of programmes***

The shift of the application process to the commune-level has also been credited by key informants with improving awareness of disability-targeted programmes, as local officials are more involved in outreach. Among people with disabilities in the quantitative survey, almost 60% were aware of disability-targeted social protection programmes, and almost half had heard about them from programme officials directly. The Disability Allowance and health insurance (State-subsidised or otherwise) were both the most well-known and deemed most useful among people with disabilities.

*“I think that health insurance brings a lot of benefit, we should buy a health insurance card in case of illness. My entire family bought health insurance because of having fears about being ill.”* (Caregiver of an 11-year-old girl, who is not receiving the Disability Allowance)

Still, many people with disabilities were unclear about the eligibility requirements for programmes. The lack of clarity could dissuade people from applying, or result in confusion and frustration if applications were unsuccessful.

*“I cannot move my left hand, my right hand is weak. I had polio when I was young. I made a dossier and tried to apply several times but was not successful.”*

*Some other people who are like me receive monthly social welfare but I do not. I don't know why. I tried many times but always failed. That's why I don't want to try more"* (32 year old man who is not receiving the Disability Allowance)

While awareness of the Disability Allowance and CHI was high, few people (including people who were already receiving the Disability Allowance) were aware of the full range of entitlements available to them. For example, as illustrated in Table 3, among Disability Allowance recipients fewer than 15% were aware of most other benefits. Lack of awareness of benefits such as transportation discounts and free vocational training likely dissuades applications from people with less severe impairments, who although not eligible for social assistance or subsidised health insurance, could still benefit from other programmes. Programme administrators similarly had little awareness of these other benefits, and thus were not in a position to offer information to recipients on how to access them. Among people with disabilities who were aware of additional entitlements, they were generally perceived to be of little value.

### ***Broader disability-inclusive planning***

For many disability-targeted entitlements, the perception of low utility was in large part linked to concerns about the quality and availability of the linked services. For example, vocational training tends to be urban-based and was reported to not provide people with disabilities with employable skills based on their individual abilities and the demands of the local job market. Similarly, while transportation discounts address financial barriers to access, limited availability and accessibility of public transportation restricts the utility of this benefit.

*"For people [with disabilities], they can have an exemption for using a public bus. However, there was no way for people with a wheelchair to get onto a public bus. It's a problem."* (Key informant)

Additionally, physically inaccessible facilities and the absence of information provided in alternative formats could also serve as a barrier to applying for both disability-targeted and non-targeted programmes, as well as using benefits once approved. Social exclusion could also prohibit participation in non-targeted schemes. For example, many working-aged people with disabilities were either not employed

or in irregular, low pay-work, almost exclusively within the informal sector. Consequently, they were not eligible for employer-subsidised social insurance and, due to high levels of poverty and the irregularity of their work, the high monthly premiums attached to voluntary schemes were prohibitive.

### ***Attitudes on disability and need for social protection***

Norms around who is considered “deserving” of social protection, particularly social assistance, could influence decisions to apply as well as assessment outcomes. For example, functional decline due to ageing was often not considered to be a “legitimate” form of disability, by people with disabilities and administrators alike, and some argued that the benefit should be targeted for people who are poor.

*“The government should support children with congenital abnormalities not elderly people like us. It is good if the government has social support for elderly people like us, we are getting old and weak, often being sick and difficult to move around. However, I don’t make a dossier [to apply for the Disability Allowance]. I think it should be for people who are living in poorer living conditions than me. It is ok if they come to see me and make a dossier for me, if not, I am not going to ask for it.”* (65-year-old woman, not receiving the Disability Allowance)

Furthermore, although eligibility for disability-targeted social protection is based only on the presence of disability as determined by the scoring system outlined in Joint Circular 37, some officials noted considerations of other circumstances could sway assessment outcomes.

*“Using forms in Decree 28 and the Joint Circular sometimes is difficult. Children for example, if they are children and cannot be in the severe category, we need to flexible, for children to receive social welfare.”* (Key informant)

*“We consider about living conditions, if they are in economic difficulty, we can be more flexible. It is not in the guideline but we can adjust it in practice.”* (Key informant)

Typically, this use of discretion by assessors was reported to result in favourable outcomes for applicants (i.e. approval of application, categorisation to a higher degree). However, in certain cases straying from official guidelines could result in exclusion from disability-targeted programmes. For example, it was noted that local programme officials often play a gate-keeping role in encouraging or dissuading applications. In particular, people who would be unlikely to qualify for social assistance were often dissuaded from applying, even if they would be eligible for benefits earmarked for people with ‘mild’ disability degree classifications.

## **Discussion**

This study aimed to measure access to social protection among people with disabilities in Vietnam and explore factors that support or hinder participation in relevant programmes. This research contributes to a relatively limited evidence base on inclusion of people with disabilities in social protection, which is needed to inform planning and delivery of systems [13].

Few studies have measured participation of people with disabilities in targeted and non-targeted social protection in a population-based sample, or have compared access to people without disabilities. Overall, this research found relatively high uptake of many social protection programmes among people with disabilities. Health insurance was almost universally accessed, while slightly over half of people with disabilities were social assistance beneficiaries (predominantly the Disability Allowance). People with disabilities were more likely to be recipients of both health insurance and social assistance compared to people without disabilities. In contrast, no person with a disability reported participating in social insurance, with many ineligible as they were not employed in the formal sector or worked too irregularly to afford regular contributions.

While access to disability-targeted social assistance and health insurance was high, a large proportion of people with disabilities were not participating in programmes that they were eligible for. In addition to the 45% of people with disabilities not receiving any form of disability-targeted social protection, many social protection beneficiaries were not accessing the full spectrum of benefits that were available to them. Key challenges to accessing social protection included: low awareness or

perceived utility of certain entitlements, poor quality and availability of linked services, biases in assessment criteria and among programme staff, and geographic and financial barriers for people with disabilities who needed to go to a central level to make their application. Some of these challenges, particularly challenges in administering a disability assessment and low levels of awareness of availability of programmes, have been noted in other research [13, 28-32].

Still, this research also highlighted several strengths to the design and delivery of social protection in Vietnam. The coverage of disability-targeted benefits in Cam Le (40%), was much higher than previous estimates for Vietnam (9.7%) and the Asia-Pacific region (9.4%) [3]. Part of these differences may reflect differences in methodology, as this study used a direct survey approach, while other reported figures are estimates derived from applying the 15% global disability prevalence to Vietnam. Access of people with disabilities to many disability-targeted and non-targeted programmes appears to have expanded in recent years. For example, the number of Disability Allowance recipients almost doubled from 2009 to 2014, from less than 385,000 to over 700,000 [33, 34]. Similarly, in 2001-2002, only 19% of people with severe disabilities nationally reported having health insurance [35]. This study, which also broadens the scope of disability, indicates that over 90% of people with disabilities were insured.

Some recent policy changes are likely to have had positive impacts on access. Notably, the introduction of Decree 28 and the Joint Circular 37 was credited by key informants in this study as substantially reducing geographic and financial barriers to access. These policies also transferred authority to local government bodies, increasing awareness of programmes and ease of administration. The benefits of moving away from purely medical assessments to more functioning-based protocols is supported in other research as more equitable, in line with a rights-based approach and easier to implement as they are not reliant on often limited specialised resources and expertise [11, 28, 36-39]. While evidence from Cam Le indicates most social recipients undergo the predominantly functioning-based assessment at the DDDC, determinations for certain groups – for example young children and people with mental health conditions – still rely heavily on medical assessments. While



policy changes are still being explored in Vietnam to improve assessments for these groups, identifying appropriate tools is a global challenge [40].

Further research is needed to understand how access to social protection varies in other regions of Vietnam, as well as in other contexts internationally. For example, means-testing and conditionality attached to the receipt of social assistance are common features of social protection programmes in other countries [3, 28]. Yet emerging evidence suggests that people with disabilities may face additional challenges accessing these types of schemes. For example, with means-testing, eligibility thresholds rarely consider extra disability-related costs, which can alter determinations of who is considered to be poor [12, 13, 28]. One study in Vietnam found that consideration of disability-related costs would increase the poverty rate among people with disabilities from 16.4% to 20.1% [41], which would have important implications if programmes were means-tested. People with disabilities may also have reduced access to conditional cash transfers, due to greater challenges complying with conditions (e.g. school attendance for children with disabilities in the absence of accessible schools) [28, 42].

In Vietnam and other countries, studies indicate that people with disabilities are more likely to be living in poverty and experience barriers to inclusion in areas such as work, education and social participation [8, 34, 43-47], indicating a high need for social protection and other interventions. Studies are now needed to assess the effectiveness of social protection programmes in meeting their intended aims of reducing poverty, increasing access to key services and improving livelihoods.

### **Strengths and limitations**

There are several limitations that should be considered when interpreting the findings of this study. Cam Le is urban, relatively affluent, and was identified by stakeholders as having a relatively well-functioning social protection system and adequate availability of disability-related services. Consequently, some of the district-level results from this study may not reflect the situation across all of Vietnam. Coverage is likely lower in other areas, while certain barriers might be more pronounced elsewhere, particularly in remote districts.

Additionally, the Washington Group questions used to define disability in the quantitative surveys do not capture all forms of functional limitations. In particular, no questions ask about mental health, such as depression/anxiety, and it is not intended for use in children under five [48]. Our use of this tool would therefore have led to underrepresentation of these groups in our study. However, the experience of these groups is explored through the policy analysis and qualitative research.

Strengths include the use of mixed methods, which allows for a more comprehensive investigation into our research aims. The use of qualitative and quantitative research in addition to a national policy analysis enables us to corroborate and contrast findings across different methods and respondents, which ultimately both broadens and deepens our understanding of the strengths and weaknesses of designing and delivering social protection that is accessible to people with disabilities in Vietnam.

## Conclusion

Access to social protection among people with disabilities in Cam Le, Vietnam is relatively high, particularly for disability-targeted social assistance and health insurance. While Vietnam's social protection system includes many examples of good practice in disability-inclusive social protection, gaps remain in extending coverage and increasing use of certain benefits. Addressing these challenges is essential for fulfilling the commitment in the UNCRPD and the SDGs of "social protection for all".

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## Paper 5: Access to social protection among people with disabilities: Mixed methods research from Tanahun, Nepal

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#### SECTION A – Student Details

Student	Lena Morgon Banks
Principal Supervisor	Prof Hannah Kuper
Thesis Title	Investigating disability-inclusion in social protection programmes in low and middle income countries, with case studies from Vietnam and Nepal

If the Research Paper has previously been published please complete Section B, if not please move to Section C

#### SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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#### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	European Journal of Development Research
Please list the paper's authors in the intended authorship order:	Lena Morgon Banks, Matthew Walsham, Shailes Neupane, Saurav Neupane, Yogendra Pradhananga, Mahesh Maharjan, Karl Blanchet & Hannah Kuper
Stage of publication	In press

#### SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Led on conceptualisation (development of methods, e.g. creation of questionnaires), data collection, analysis for quantitative component. For qualitative component, organised findings into the themes as presented in the paper (data collection, coding and preliminary analysis conducted by co-authors). Wrote the full original draft, which was reviewed by the other co-authors. Responsible for submitting to the journal and incorporating feedback from the journal's peer review.
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Student Signature:

Date: Mar 28, 2019

Supervisor Signature:

Date: Mar 28, 2019



## **Access to social protection among people with disabilities: Mixed methods research from Tanahun, Nepal**

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## **Abstract**

While people with disabilities are often targeted as key beneficiaries of social protection, there is little evidence available on their participation in existing programmes. This study uses mixed methods to explore access to disability-targeted and non-targeted social protection programmes in Nepal, particularly the District of Tanahun. In total, 31% of people with disabilities had Disability Identification Cards, which entitles them to a range of different social protection benefits depending on the card level, including disability-targeted social assistance (received by 13% of people with disabilities). Overall, 37% of people with disabilities received social assistance, which was higher than for people without disabilities (21%). The most commonly accessed form of social assistance was the Old Age Allowance, which had universally high coverage amongst both people with and without disabilities. Uptake of disability-targeted social protection entitlements other than social assistance (e.g. scholarships, discounted transportation and health services) was generally low. Factors impacting upon access included the geographic and financial accessibility of the application process, procedures for determining eligibility and compliance of service providers.

## **Introduction**

Social protection systems are an integral component to most governments' strategies for poverty reduction, as well as broader social and economic development [1]. Although conceptualisations vary, social protection may be defined as "public actions taken in response to levels of vulnerability, risk, and deprivation which are deemed socially unacceptable within a given polity or society" [2]. Aims of social protection similarly differ, with some focusing narrowly on protecting minimum living standards, while more "transformational" approaches viewing social protection as a tool to develop stronger livelihoods, tackle chronic poverty and address social inequalities [3].

Almost all countries, including low- and middle-income countries (LMICs), have put in place some social protection initiatives, with many continuing to focus on expanding their content and coverage, as well as improving their impact [4]. There



are variety of instruments that may fall under the banner of social protection [5]. Core components of social protection are social assistance and social insurance [6]. Social assistance refers to non-contributory transfers of cash or kind to groups deemed vulnerable to or currently in poverty (e.g. conditional/unconditional cash transfers, food assistance). Social insurance programmes in turn are typically contributory, and are designed to mitigate risks that may be encountered throughout the life-course (e.g. illness and injury, unemployment, loss of income in old age, natural disasters). Under broader definitions of social protection, labour market regulations (e.g. minimum wage, non-discrimination legislation) or interventions to promote equitable access to services and enjoyment of basic rights may be considered as social protection [5, 7]. In LMICs, however, social assistance has been the main pillar of social protection [8].

Developing and strengthening social protection systems is a core aim of the International Labour Organization's Social Protection Floor Recommendation (2012) and the 2015-2030 Sustainable Development Goals (SDGs) [9]. For example, SDG Target 1.2 highlights social protection as a key input to "end poverty in all its forms", while other SDGs and their targets specify social protection as central for achieving a range of goals, such as universal health coverage, gender equality, reducing inequality and decent work for all [4]. While acknowledging that all citizens should be provided with certain nationally-appropriate guarantees – such as income security and access to essential services – it is acknowledged that social protection is particularly important for groups and individuals at a higher risk of poverty and facing other forms of marginalisation [5, 10].

People with disabilities – who comprise upwards of 15% of the global population – are often considered as key beneficiaries in national and international social protection strategies [11-13]. Disability is defined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as including people "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" [14]. People with disabilities may be targeted for inclusion in social protection due to high levels of economic and multidimensional poverty, as well as frequent social exclusion and marginalisation [5, 15, 16]. For example, in a

recent systematic review of 150 studies in LMICs, 81% found people with disabilities were more likely to be economically poorer compared to people without disabilities [17]. Similarly, other studies have found people with disabilities experience high levels of multidimensional poverty, such as malnutrition and lower levels of health, barriers to accessing education and healthcare, and exclusion from decent work and social participation [18-21]. Poverty may even be underestimated amongst people with disabilities, due for example to high out-of-pocket spending on disability-related items (e.g. personal assistance, rehabilitation and assistive devices), intra-household discrimination in the allocation of resources and opportunities, as well as structural inequalities that prevent equal participation in society [13, 15, 22]. The combination of spending on extra disability-related costs, social exclusion and opportunity costs from caregiving provided by other household members can lead to increased vulnerability to poverty amongst people with disabilities and their households [23, 24].

In addition to this needs-based argument, the right of people with disabilities to inclusion in social protection is established in international treaties such as Article 28 of the UNCRPD and Article 22 and 25 of the Universal Declaration of Human Rights [25, 26]. As mandated in the UNCRPD's Article 28, people with disabilities have the right to equitable access to mainstream social protection programmes – such as health insurance, pensions and other benefits where eligibility is not dependent on disability status [15, 27]. Further, disability-targeted programmes may be required to address disability-specific concerns such as the need for rehabilitation and assistive devices, workplace supports or specialist education. People with disabilities also frequently face additional costs, such as for extra transportation or medical expenses that can deepen inequalities in standards of living compared to people without disabilities [4, 22, 27]. Subsidising these additional costs and promoting access to services and supports required for full and equal participation are typically the main objectives of disability-targeted programmes. Overall, a central aim of disability-inclusive social protection across both mainstream and targeted schemes is addressing social exclusion [15].

For people with disabilities to partake in any of the intended benefits of social protection, they must first be able to access programmes. A recent systematic review

found little evidence across LMICs on whether people with disabilities were actually participating in social protection programmes, despite the emphasis placed on targeting people with disabilities as key recipient groups [28]. Available evidence, however, suggests coverage is well below need and many eligible individuals are not accessing programmes [29-31]. Low coverage may be linked to broader social exclusion of people with disabilities. For example, policymakers may not adequately take into account the needs of people with disabilities when designing and delivering social protection – such as in aligning programmes to address disability-specific vulnerabilities to poverty or ensuring application procedures are accessible - due to discrimination, lack of understanding or insufficient political will [24]. For disability-targeted programmes, disability assessment procedures are a frequent cause of exclusion if eligibility criteria are poorly defined or administrative capacity is insufficient to properly implement them [23, 24].

High levels of exclusion are reflected in recent efforts by the International Labour Organisation to estimate coverage of people with disabilities in disability-targeted programmes, using regional prevalence estimates of disability from the 2002-2004 World Health Surveys combined with country-level programme enrolment figures. Under this approach, it was estimated that 27.8% of people with “severe” disabilities are recipients of a disability-targeted cash benefit, with access differing substantially across regions, with coverage lowest in Asia and the Pacific at 9.4% and highest in Eastern Europe (97%) [4]. However, these figures are based on modelled estimates, rather than direct survey, and the definition of “severe” disability is unclear. Further, little evidence is available on how enrolment differs amongst people with disabilities, enrolment in non-targeted schemes, or factors affecting accessing both mainstream and targeted programmes [28].

Consequently, this study explores participation of people with disabilities in social protection programmes, with Tanahun district of Nepal as the study setting. This research uses mixed methods to assess coverage (through direct survey), how coverage varies amongst people with disabilities (e.g. by gender, impairment type), as well as challenges and facilitators to enrolling in or using relevant social protection programmes. This research benefits from a population-based study design and from the use of the Washington Group question sets for measurement of disability, which

are internationally validated and recommended for robust and comparable disability statistics, including in the tracking of progress towards the SDGs [32].

## **Overview of Social Protection Entitlements in Nepal**

Social protection entitlements in Nepal are gradually expanding, particularly social assistance [33]. Most social protection entitlements are targeted to various groups deemed to be at greatest risk of poverty and marginalisation, including people with disabilities [34]. There are also a few schemes open to the broader population – namely for social insurance and health care provisions – although these are more limited in scope and coverage.

While specific aims of social protection in Nepal have not been formally outlined, they are meant to “maintain a degree of equity among citizens” and ensure all citizens are able to “live a decent life” [35]. Social protection entitlements focus both on alleviating deprivation in income (i.e. social assistance), as well as fostering broader social inclusion (e.g. through educational scholarships, healthcare discounts, employment supports) [36]. The range of entitlements offered in Nepal recognise both economic and social challenges facing people with disabilities and other groups experiencing poverty or other forms of deprivation [37].

### ***Disability-targeted social protection entitlements***

Key disability-targeted entitlements are listed in Table 1 [38, 39]. In order to be eligible for these entitlements, people with disabilities must first undergo an assessment of disability and receive a disability card. To apply for a disability card, an individual must first submit an application to the Women and Children’s District Office (WCDO). The application consists of the following: a letter from the applicant’s Village Development Committee (one of the lowest administrative units in Nepal) verifying their identity and place of residence, birth certificate or citizenship card, photographs, and completed application form. The application form includes questions on self-reported type and severity of the disability, any difficulties the person faces because of their disability (e.g. in doing daily chores, working), and the need for assistive devices. Medical documentation and references from Disabled Peoples’ Organizations (DPOs) can also be included to support the application, although they are not an explicit requirement.

Once the application is processed by the WCDO, the applicant is called for an in-person evaluation, which is typically conducted by the Disability Identification Committee. The Disability Identification Committee comprises representatives from local government offices (e.g. District Health Office, WCDO, District Development Committee) and, if available, from a registered DPO operating in the district. Assessments of disability are informed by an in-person evaluation on the applicant's level of difficulty in performing daily activities and participating in social life, gauged through observation and responses in the application form.

Based on the results of the assessment, an individual is classified into one of four disability card categories (from most to least severe: red, blue, yellow, white). The disability card category is based on an assessment of the level of support needed:

- Red – “complete disability” – difficulty in performing daily activities, even with the help of others.
- Blue – “severe disability” – difficulty in performing daily activities without the help of others.
- Yellow – “moderate disability” – able to perform daily activities and participate in social life if environment is barrier-free, and appropriate training and education are provided.
- White – “mild disability” – ability to perform daily activities and participate in social life if environment is barrier-free.

The disability card classification determines which social protection benefits a person is eligible to receive. While the Disability Allowance is reserved for people with the two most severe card categories (red, blue), the remainder of the benefits are open to disability cardholders of any colour classification. Nationally, 198,788 people were registered as receiving disability cards in the fiscal year 2014/15 [40]. Slightly under half (93,858) have yellow or white cards, which means they are not eligible for the Disability Allowance.

For red and blue cardholders to receive the Disability Allowance, they must submit an additional application to their local Village Development Committee (VDC). Separate applications are also needed for educational scholarships, while other

benefits (e.g. health and transport discounts) can be accessed through presentation of the disability card at the point of use.

**Table 1. Overview of disability-targeted social protection entitlements in Nepal**

Entitlement	Eligibility (card level)	Description of entitlement
Disability allowance	Red, blue	<i>Unconditional monthly cash transfer.</i> NR 1000 (US\$10) (red), NR 300 (US\$3) (blue) (as of fiscal year 2015/16)
Health discounts	Any classification	Various (e.g. discounts on some drugs/health services, reservation of 2 hospital beds in facilities with over 50 beds)
Education supports	Any classification	<i>Scholarships:</i> from NR 100-3000 (US\$1-28), based on area of residence and whether a student boards at school, for children in grade 1-8. Free post-secondary tuition at Tribhuvan University
Vocational training & employment supports	Any classification	Various (e.g. 5% quota in public sector, free vocational training from approved sources, discounts on income tax, early retirement for civil servants with disabilities)
Transportation discounts	Any classification	Free or subsidized public transportation.

### ***Non-disability targeted social protection entitlements***

People with disabilities may also be eligible for programmes aimed at other targeted groups, if they meet their eligibility criteria. For example, children may receive educational scholarships for reasons other than disability, such as if they are a girl living in poverty, are from the Karnali zone or belong to the Dalit caste. The amounts provided through these scholarships vary, but are typically less than is provided for children with disabilities. Similarly, unconditional social assistance is available to older adults (aged 70+ or 60+ for the Karnali zone/members of Dalit caste), single women over 60, widows, indigenous groups considered to be endangered and for children under 5 from the Dalit caste or who live in the Karnali zone. Amounts range from NR 200-1000 per month (US\$2-9). It is important to note that an individual

cannot receive more than one type of social assistance at any one time. People receiving a pension, or on a government salary, are ineligible to receive social assistance [41].

Regarding pension schemes, Nepal has been expanding available schemes, although presently all are restricted formal sector employees. Pensions are mandatory for public sector employees, and can be accessed after 20 years of services (16 for military, 13 for people with disabilities) [35]. Voluntary contributory pension schemes are available for formal sector employees, in which contributions are exempt from income tax. In addition to pensions, public sector employees and employees of formal sector businesses with at least ten employees have legal protections covering maternity and sickness leave, as well as provisions for injury, disablement and death due to work-related accidents.

Lastly, all Nepali citizens are entitled to some basic healthcare provisions. This includes coverage of some services at lower level health posts and 60 prescription drugs free of charge. Older adults aged 70 and above can access additional health services without charge, up to an annual limit of NR 4,000 (US\$38).

## **Methods**

A mixed-methods approach was used to assess access to existing social protection programmes. In-depth qualitative and quantitative research was undertaken in one district in Nepal to measure coverage and uptake of social protection benefits, as well as barriers and enablers to enrolment among people with disabilities. Qualitative interviews were also conducted with national-level stakeholders to contextualise findings within national policies and programmes. For all components, disability-targeted entitlements were the main focus, although non-disability targeted programmes were also explored where possible.

Ethical approval from this research was granted from the Ethics Committee at the London School of Hygiene & Tropical Medicine and the Nepal Health Research Council. Informed written consent was obtained from all study participants prior to beginning any interviews. For children below 16 years (age of consent) and people

with impairments that severely limited their ability to understand/communicate, a carer answered on their behalf as a proxy.

Data collection was undertaken between August-September 2016.

## **Setting**

A rapid policy analysis was conducted in 2015 of social protection systems in Asia and the Pacific and the extent to which they were inclusive of people with disabilities [42]. From this analysis, Nepal was selected as a study site as it was identified as having a relatively strong social protection system, which had made concerted efforts to be inclusive of people with disabilities, particularly through multiple disability-targeted programmes. Consequently, studying Nepal's system offered an opportunity to identify and describe examples of good practice in disability-inclusive programme design and implementation.

Within Nepal, data collection was undertaken in Tanahun. Tanahun is a predominantly rural district in Province No. 4, which is part of the Hills region. Tanahun was selected as the study setting after consultation with in-country stakeholders who recommended this district due to its strong network of DPOs, adequate availability of disability-support services and relatively well-functioning social protection administration. To complement district-level research, qualitative interviews with national-level stakeholders were used to provide an overview of the national context.

## **Quantitative research in Tanahun**

Quantitative data collection included a population-based survey of disability across Tanahun, with a nested case-control to compare awareness of and enrolment in social protection programmes between people with and without disabilities.

The 2011 national census was used as the sampling frame for the population-based survey. A two-stage sampling strategy was employed based on methodology used in other surveys [43]. In the first stage, probability-proportionate-to-size sampling was undertaken to select 30 clusters (wards of VDCs) in Tanahun. In the second stage, 200 people aged five years and older were enumerated and recruited in each cluster through compact segment sampling. The sample size of the population-based



survey was set at 6,000 to ensure the identification of adequate numbers of people with disabilities for the case control study. For the case control, a sample of 240 cases with disabilities and 240 controls without disabilities was powered to detect an odds ratio of 1.9, assuming 80% power and a prevalence of exposure (e.g. poverty, the main measure of the broader study) of 25% among controls.

Disability was measured using two age-specific question sets created by the Washington Group on Disability Statistics, a group established under the United Nations Statistical Commission [44]. This comprised an accepted modification of the Washington Group Extended Question Set on Functioning and the UNICEF/Washington Group Questions on Child Functioning [45, 46]. The modification of the Extended Set is approved in Washington Group guidelines, and has been used in other research [47, 48]. These question sets are in line with the World Health Organization's International Classification of Health, Disability and Functioning – a commonly used framework used for conceptualising disability [13, 49] – as they focus on an individual's ability to perform routine activities of daily living. These tools have been validated in a variety of settings and are recommended by a wide range of global stakeholders for providing robust and internationally comparable estimates of disability [32].

Both the adult and child question sets focus on similar activities. For most questions, participants can select one of four response options describing their level of difficulty in performing each activity: none, some, a lot or cannot do at all. Anxiety and depression in the adult set was assessed through a two-part question on intensity and frequency of symptoms. For the purpose of this study, disability was defined as:

- Adults (16+):
  - Reported “a lot of difficulty” or “cannot do” in at least one of the following domains: seeing, hearing, walking/climbing, communicating (understanding/being understood), remembering/concentrating, self-care, upper body strength, fine dexterity.
  - Reported experiencing symptoms of anxiety or depression “daily”, at a level described as “a lot”
- Children (5-15):

- Caregiver reported that compared to other children of the same age, the child experienced “a lot of difficulty” or “cannot do” in at least one of the following domains: seeing, hearing, walking, self-care, understanding, being understood, learning, remembering. Child was worried/sad “a lot more” often than other children.

Interviewers were instructed to ask each household member about his/her functioning directly, if the person was over the age of consent (16+ years) and present at the time of the household visit. Household heads/caregivers reported on children’s and absent members’ functioning. The cut-offs used in this study to define disability are in line with the Washington Group guidelines [50], and are comparable to eligibility criteria for disability-targeted social protection in Nepal. Further, a disability severity score was created by summing the level of difficulty across all activities (no difficulty=0, some difficulty=1, a lot of difficulty=2, cannot do=3; anxiety/depression=3) and dividing it over the maximum possible score for the two question sets (27 for adults, 21 for children) to obtain a score from 0-100%. This method for constructing disability severity has been used in other research [51].

All individuals identified during the household survey as having a disability were recruited into the case-control study. The case-control questionnaire explored in greater depth need for, awareness of and participation in disability-targeted and non-targeted social protection programmes. Each person with a disability (case) was then matched to a person without a disability (control), who was of similar age (+/- 5 years), the same sex and resided in the same cluster. Controls could not be from households with members with disabilities. Additionally, 92 people with disabilities were recruited from registers of the Disability Allowance. To select participants from registers, 2-3 people were randomly selected from non-selected segments of included clusters. These participants received the same questionnaires as cases recruited in the population-based survey, but they were not matched to controls. All register-recruited and population-based cases who received the Disability Allowance received a third questionnaire, which included questions about the application experience.

Trained data collectors administered questionnaires, which had been translated into Nepali and created using Open Data Kit (ODK), using computer tablets. Multivariate

regression using STATA 15 was undertaken to compare participation in various schemes between respondents with and without disabilities, controlling for age, sex and location.

### ***Qualitative research***

In-depth, semi-structured interviews were carried out with people with disabilities who were and were not recipients of social protection (namely disability-targeted programmes), as well as stakeholders in disability and/or social protection in the district. People with disabilities were interviewed about their awareness of disability-targeted programmes. Social protection recipients were asked about their experience applying for and participating in different schemes. For stakeholders, interviews focused on social protection policies and programmes, strengths and challenges of existing programmes, including factors affecting access for people with disabilities.

A purposive sample of participants with disabilities was recruited using data collected through the population-based survey. Participants were selected to reflect variation in terms of sex, age (children, working-age and older adults), impairment type and geographic distribution (rural vs urban). Adults with disabilities were interviewed directly; however, in some instances, proxies were used if the individual's impairment severely affected his/her ability to understand or communicate (e.g. people with profound hearing impairments but who had never learnt sign language, severe cognitive/intellectual impairments), even with available supports (e.g. sign language, visual aids). For children, interviews were predominately with caregivers, as young children were unlikely to be directly involved in decisions to apply or manage the application process.

In addition, national-, district- and community-level stakeholders were selected through recommendations from in-country advisors (e.g. National Federation of Disabled, Nepal) and snowball sampling. Stakeholders included representatives from relevant government agencies, United Nations' agencies, non-governmental organisations (NGOs), DPOs, disability service providers and administrators responsible for social protection implementation.

Interviews with all participants were transcribed in Nepali and a thematic approach was used to analyse findings.

### **Description of the study samples**

For the population-based survey, 6,000 household members were included and 5,692 screening for disability (response rate: 94.9%). Overall, 214 individuals were identified as having a disability (prevalence: 3.8%, 95% CI: 3.3-4.3%). Prevalence of disability was slightly higher in men compared to women (aOR: 1.4, 1.0-1.7), and increased substantially with age (from 1.5% in children 5-18 to 19.6% in adults 76+,  $p<0.001$ ).

Overall, 418 people from the population-based survey (209 cases and 209 controls) took part in the case control study (response rate: 97.9%). Cases and controls were well matched by age, gender and location, as there were no significant differences between groups in these characteristics. An additional 92 people with disabilities were recruited from Disability Allowance registers, who were not matched to controls, but received similar questionnaires.

For the qualitative research, 35 people with disabilities were recruited (response rate=100%). Of the 35 people, nine were with caregivers of children and 14 involved direct interviews with adults with disabilities. The remaining 12 adults involved people with severe intellectual/cognitive and/or communication impairments. In these instances, proxies either assisted in providing additional information ( $n=9$ ) or answered fully on behalf of the participant ( $n=3$ ). Within this group, 28 participants had a disability card. By impairment type, the following breakdown was observed: physical/mobility ( $n=17$ ), communication ( $n=10$ ), vision ( $n=5$ ), hearing ( $n=5$ ), psychosocial ( $n=5$ ), intellectual/cognitive ( $n=5$ ); 14 respondents had multiple impairments. Respondents ranged in age from 5-86 years old (10-17 years:  $n=9$ , 18-64 years:  $n=22$ , 65+ years:  $n=4$ ) and there was a near equal mix by gender (female,  $n=19$ ). For key informants, 13 district- and community-level and 15 national-level stakeholders were interviewed.

## Findings

### Enrolment in social protection

Overall, 65 (31.1%) people with disabilities identified during the population-based survey had a disability card (Table 2). This included 34 (52%) people who were eligible for the Disability Allowance (red card, n=13; blue card, n=21). The remainder (47%) had lower level disability cards (yellow card, n=18; white card, n=13). Over a third of all people with disabilities identified in the survey received some form of social assistance, which was significantly higher in comparison to people without disabilities (aOR=3.0, 95%CI 1.6-5.3). The Old Age Allowance was the predominant form of social assistance received, among both people with and without disabilities. The Old Age Allowance had universally high coverage, as over three-quarters of eligible older adults were enrolled. Coverage of the Disability Allowance was lower at 13.4%. No one who did not meet the study's definition of disability was receiving the Disability Allowance, indicating low inclusion errors. However, six people (7.7%) who had received a disability card of an eligible classification were not receiving the Allowance.

	People with disabilities (n=209)	People without disabilities (n=209)	aOR (95% CI) <sup>Ω</sup>
<b>Disability card</b>	65 (31.1%)	n/a	n/a
Red	13 (6.2%)	n/a	n/a
Blue	21 (10.0%)	n/a	n/a
Yellow	18 (8.6%)	n/a	n/a
White	13 (6.2%)	n/a	n/a
<b>Social assistance</b>			
Any social assistance	77 (36.8%)	44 (21.1%)	3.0 (1.6-5.3)*
Disability Allowance	28 (13.4%)	0 (0%)	n/a
Old Age Allowance <sup>1</sup>	41 (80.4%)	37 (77.1%)	1.0 (0.3-3.2)
Single Woman/Widow's Allowance <sup>2</sup>	8 (28.6%)	5 (23.8%)	1.7 (0.6-4.4)
<b>Social insurance</b>			
Receiving pension payments <sup>3</sup>	17 (8.1%)	18 (8.6%)	1.0 (0.5-2.0)

<sup>Ω</sup>Adjusted for age, sex and location (rural/urban)

\*Statistically significant

<sup>1</sup> Among adults age 70+ or 60+ if Dalit caste, as per eligibility requirements

<sup>2</sup> Among widows, and single women aged 60+, as per eligibility requirements

<sup>3</sup> Individual did not necessarily accrue the pension him/herself. This includes family members receiving pensions on behalf of a deceased pension-recipient.

**Table 2. Social protection coverage among people with and without disabilities (population-based survey participants only).**

Disability cardholders are entitled to a range of benefits other than the Disability Allowance. However, uptake of most of these benefits was low (Table 3).

Transportation discounts and educational scholarships had the highest uptake (25.5% and 13.0% respectively). Uptake of these benefits varied by disability card level, with people with the lowest assessed severity more likely to use benefits such as transportation discounts and scholarships.

	Linked benefits			
	Transportation discounts	Education discounts (aged ≤17)	Discounted healthcare	Vocational training (aged ≥18)
<b>All cardholders (n=157)</b>	40 (25.5%)	3/23 (13.0%)	18 (11.4%)	8/135 (5.9%)
<b>Disability Card level</b>				
Red (most severe) (n=60)	11 (18.3%)	0/13 (0%)	7 (11.7%)	1/47 (2.1%)
Blue (n=65)	16 (24.6%)	2/8 (25%)	7 (10.8%)	6/57 (10.5%)
Yellow (n=18)	9 (47.4%)	1/2 (50%)	3 (15.8%)	0/17 (0%)
White (least severe) (n=13)	4 (30.8%)	0/0 (0%)	1 (7.7%)	1/13 (7.7%)
<i>p-value</i>	0.08	0.07	0.90	0.21
<b>Disability Allowance</b>				
Recipient (n=118)	25 (21.0%)	1/21 (11.1%)	14 (11.8%)	6/99 (6.1%)
Non-recipient (n=38)	15 (38.5%)	1/2 (50%)	4 (10.3%)	2/35 (5.8%)
<i>p-value</i>	0.04*	0.02*	0.80	0.37

**Table 3. Uptake of entitlements among recipients of disability-targeted social protection (population-based survey and register-recruited participants)**

Table 4 compares characteristics of people with disabilities who were and were not disability cardholders. Overall, coverage was highest for children and adults under 50. Coverage was lowest for people with sensory limitations as well as anxiety and depression. People with multiple functional limitations and limitations in self-care were particularly likely to have a disability card.

	<b>Disability cardholder (n=157)</b>	<b>No disability card (n=144)</b>	<b>aOR (95% CI)<sup>a</sup></b>
<b>Gender</b>			
Male	89 (53.6%)	77 (46.4%)	Reference
Female	68 (50.4%)	67 (49.6%)	0.9 (0.5-1.5)
<b>Location</b>			
Urban	44 (53.7%)	38 (46.3%)	Reference
Rural	113 (51.6%)	106 (48.4%)	1.1 (0.6-1.9)
<b>Age group (years)</b>			
5-18	25 (56.8%)	19 (43.2%)	Reference
19-49	84 (69.4%)	37 (30.6%)	1.7 (0.9-3.5)
50-69	42 (46.7%)	48 (53.3%)	0.7 (0.3-1.4)
70+	6 (13.0%)	40 (87.0%)	0.1 (0.04-0.3)*
<b>Functional limitation<sup>b</sup></b>			
Physical	90 (57.3%)	67 (42.7%)	1.9 (1.1-3.1)*
Sensory	49 (48.0%)	53 (52.0%)	1.0 (0.6-1.8)
Communication	76 (66.1%)	39 (33.9%)	2.3 (1.3-4.0)*
Cognitive	72 (67.3%)	35 (32.7%)	2.2 (1.3-4.0)*
Self-care	73 (67.0%)	36 (33.0%)	3.1 (1.8-5.4)*
Anxiety/depression	11 (44.0%)	14 (56.0%)	0.4 (0.2-0.9)*
Multiple	110 (61.8%)	68 (38.2%)	3.1 (1.8-5.4)*
<b>Severity score<sup>c</sup></b>	<b>Mean (SE)</b>	<b>Mean (SE)</b>	<b>Coefficient (95%CI) <sup>a</sup></b>
Score	0.34 (0.01)	0.21 (0.02)	0.13 (0.08-0.17)*

<sup>a</sup> Adjusted by age, sex, location

<sup>b</sup> Not mutually exclusive (i.e. sum >100%). Domains derived from Washington Group questions as follows: physical (difficulties walking, with upper body function or fine dexterity), sensory (hearing/seeing), communication, cognitive (remembering, learning and understanding).

<sup>c</sup> Total across Washington Group domains (0=no difficulty, 1=some, 2=a lot, 3=cannot do for each domain; 3=anxiety/depression), divided by maximum score (21 for children, 27 for adults). Scores range from 0-100%.

\* Statistically significant

**Table 4: Characteristics of disability cardholders compared to non-recipients with disabilities (population-based survey and register-recruited participants)**

While older adults with disabilities were less likely to have a disability card, this age group had the highest coverage of social assistance overall, in large part due to the high coverage of the Old Age Allowance (Table 5). There was no clear association between functional limitations and receipt of social assistance, although recipients had slightly higher severity scores. Similarly, no difference in the likelihood of receiving social assistance were observed by gender or location.

	<b>Social assistance</b>	<b>No social assistance</b>	
	<b>n (%)</b>	<b>n (%)</b>	<b>aOR (95% CI)<sup>a</sup></b>
<b>Gender</b>			
Male	107 (38.1%)	174 (61.9%)	Reference
Female	106 (46.3%)	123 (53.7%)	1.2 (0.7-2.0)
<b>Location</b>			
Urban	54 (40.9%)	78 (59.1%)	Reference
Rural	159 (42.1%)	219 (57.9%)	1.2 (0.7-2.1)
<b>Age group (years)</b>			
5-18	23 (23.4%)	48 (67.6%)	Reference
19-49	69 (37.1%)	117 (62.9%)	1.3 (0.6-2.6)
50-69	43 (26.2%)	121 (73.8%)	0.7 (0.3-1.4)
70+	78 (87.6%)	11 (12.4%)	14.0 (3.8-52.0)*
<b>Functional limitation<sup>b</sup></b>			
Physical	99 (63.1%)	58 (36.9%)	1.9 (1.1-3.0)*
Sensory	70 (68.6%)	143 (35.1%)	2.0 (1.1-3.4)*
Communication	79 (68.7%)	36 (31.3%)	3.3 (1.9-5.7)*
Cognitive	75 (70.1%)	32 (29.9%)	3.9 (2.2-7.1)*
Self-care	79 (72.5%)	30 (27.5%)	4.4 (2.5-7.7)*
Anxiety/depression	12 (48.0%)	13 (52.0%)	0.8 (0.8-2.0)
Multiple	123 (69.1%)	55 (30.9%)	5.7 (3.1-10.4)*
<b>Severity score<sup>c</sup></b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Coefficient (95%CI) <sup>a</sup></b>
Score	0.32 (0.17)	0.21 (0.12)	0.12 (0.08-0.15)*

N.B. Includes people with disabilities from population-based survey (n=209) and registers (n=92)

<sup>a</sup> Adjusted by age, sex, location

<sup>b</sup> Not mutually exclusive (i.e. sum >100%). Domains derived from Washington Group questions as follows: physical (difficulties walking, with upper body function or fine dexterity), sensory (hearing/seeing), communication, cognitive (remembering, learning and understanding).

<sup>c</sup> Total across Washington Group domains (0=no difficulty, 1=some, 2=a lot, 3=cannot do for each domain; 3=anxiety/depression), divided by maximum score (21 for children, 27 for adults). Scores range from 0-100%.

\* Statistically significant

**Table 5: Characteristics of recipients of social assistance (disability-targeted and non-targeted) compared to non-recipients with disabilities (population-based survey and register-recruited participants)**

### ***Factors influencing enrolment and uptake of social protection among people with disabilities***

Across study methods, several factors emerged which impacted enrolment in and uptake of social protection among people with disabilities. These factors concerned: (1) geographic accessibility, (2) financial accessibility, (3) determining eligibility, (4) understanding the application process, (5) awareness and perceived utility of programmes, and (6) compliance among service providers. These are described in



detail below. While the focus was predominantly on disability-targeted schemes, other programmes are also discussed where relevant.

### ***Geographic accessibility***

In Nepal, applications for disability cards, a precondition to receiving the Disability Allowance and other disability-targeted social protection entitlements, are processed in district headquarters. In contrast, applications for non-disability targeted social protection benefits are conducted at the more local VDCs, which are geographically nearer. As VDCs cover a relatively small catchment area, few people reported problems traveling to these offices.

Getting to district headquarters, however, was cumbersome for many people, particularly for people with mobility limitations or who lived in remote areas. Tanahun covers an area of over 1,500 km<sup>2</sup>, much of which is rural with limited roads and transportation links. The lack of accessible transportation in many parts of Tanahun and the rest of the country was noted by key informants, people with disabilities and their caregivers alike as compounding difficulties getting to application points. Mirroring these responses, in the quantitative survey of Disability Allowance recipients, over 60% of people who had successfully completed the application process for the disability card reported difficulties getting to the application point.

Furthermore, upon reaching the application office, many people were asked to provide medical documentation before their application for the disability card could be processed. Gathering the necessary documentation may involve travel to cities in other districts. For example, there are no ear, nose and throat (ENT) specialists in Tanahun, so people with hearing impairments were required to travel to Pokhara, in the neighbouring district (50km from the district headquarters of Tanahun) for assessment. In fact, many respondents reported traveling to Pokhara and other cities to get medical documents for a range of different impairments for their applications. These difficulties were also reinforced in the survey of Disability Allowance recipients, as 85% reported needing a medical evaluation, which for 11% required travel outside the district.

In recognition of these and other barriers, outreach camps are organised by the WCDO, the District Health Office and community-based organisations. These camps are held in various locations throughout the district so that people can submit

applications and undergo an assessment of disability without travel to the district headquarter. Outreach camps were started in Tanahun but have since been rolled out throughout Nepal, and are now mandated in the Disability Identification Card Distribution Guidelines 2008. Still, key informants involved in the process note that while initially effective, they are looking to “cut off” outreach camps as they believe most people have been reached and anyone remaining *“should come on their own as it’s too expensive to organise outreach programmes for a few people.”*

### ***Financial accessibility***

Officially, there are no direct costs (i.e. application fees) for submitting applications for any social protection programmes. However, 20% of surveyed Disability Allowance recipients reported paying nominal fees at application points for their application to be processed (mean: NPR 266 [US\$2.50]). Additionally, indirect costs such as for travel to application points are often incurred. For applications conducted at the VDC, these costs are typically minimal. However, to obtain a disability card, applicants must travel to the district headquarter, which can involve substantially higher transport costs. In the survey, 49% of Disability Allowance recipients noted transportation costs as a challenge. Accommodation costs are also common, as several applicants in the qualitative reported waiting for several days in the district headquarter to meet with the required officials, for the Disability Identification Committee to assemble or to gather additional documentation.

Furthermore, disability card applicants and anyone accompanying them often must forgo time spent on productive activities such as work or schooling. For example, the mother of a young woman with an intellectual impairment highlighted the financial challenges associated with applying for her daughter’s disability card. Her costs included travel to the district headquarter and fees at a government hospital for medical documentation. She was fortunate to have family members to stay with while the application process was being completed, otherwise she would have had to pay for room and board. When the application was delayed, she had to leave her daughter with relatives to complete the process, as she had to return to home: *“I requested [to the programme official], ‘Don’t do such a thing [delay assessment], sir. I am alone, no one at home. I have left cattle at home, sir. In this planting season of Jestha (May/June), don’t do this, please make it [the disability card].”* While fortunate

to have relatives near the headquarter who could assist with the application when she had to return, others do not have this support.

### ***Determining eligibility***

In comparison to disability-targeted schemes, determining eligibility for non-disability targeted programmes is relatively straightforward. All social assistance programmes require a citizenship card for people over 16 or a birth certificate for children. This documentation is sufficient to prove eligibility for the Old Age Allowance, Child's Grant and allowances for endangered indigenous groups. For the Single Women (age 60+)/Widows Allowance, a death or divorce certificate is also needed if the woman was ever married. While several participants reported difficulties gathering these documents, once obtained, assessments of eligibility are mostly clear-cut. Age, caste, ethnicity and marital status are all relatively objective criteria that can be determined directly from these documents.

In contrast, determining if a person meets disability eligibility criteria is more complex. Disability assessments for disability cards are based on an applicant's level of difficulty in performing daily activities. The language used in policies and guidelines for defining and categorising disability is broadly in-line with the UNCRPD and the International Classification of Functioning, Disability and Health [49]. For example, categorisations focus on difficulties performing daily activities, rather than the presence of medical impairments. Further, assessors are instructed to consider the role of individual and environmental characteristics (e.g. availability of support) when assessing functional status.

However, guidance documents on how to classify individuals into the four categories – namely the Disability Identification Card Distribution Guideline 2008 – were perceived as vague. Training of assessors was also reported by key informants to be limited. Consequently, in practice there is a large degree of subjectivity to the assessment. Key informants familiar with the process reported that for observable disabilities, such as physical impairments, blindness or severe intellectual impairments, assessments were straightforward. However, for mental health conditions or mild to moderate communication and developmental impairments, classifications were more challenging. For example, mental health providers reported that few of their patients had upper level disability cards even if they had a severe

mental health condition. Additionally, functional decline due to ageing is often not considered to be a disability. These attitudes on disability may lead to placement in lower card levels or the denial of a card altogether.

The lack of clarity on assessment guidelines combined with a low understanding on the impact of certain impairments among assessors may lead to an overreliance on medical documentation in determining eligibility. When the Committee cannot decide on a classification, they will request that the applicant seek a medical assessment by a specialist before making a decision on their application. In the quantitative survey, 85% of disability card holders had been asked to provide medical documentation, which was primarily obtained from the district hospital. This additional requirement can be cumbersome for applicants and leads to a more medical-model based assessment rather than one in line with the UNCRPD.

In Tanahun, mental health providers and DPOs reported collaborating with the Disability Identification Committee to improve their understanding on the disabling impact of certain impairments and conditions. Across Nepal, registered DPOs are often part of the Disability Identification Committee and can provide input into the disability assessment. In Tanahun, the involvement of DPOs was seen as beneficial by other key informants, and significant weight was given to their recommendations. However, not all districts in Nepal have a registered DPO, and the capacity of some DPOs is limited.

A final improvement to determining eligibility was the removal of quotas on the number of blue disability cardholders who could receive the Disability Allowance. Previously, these quotas led to arbitrary rationing decisions, excluding many eligible people with disabilities from the cash transfer. Since the removal of the quota, the number of Disability Allowance recipients nearly doubled between 2014/15 and 2015/16 (from 33,578 to 62,320).

### ***Understanding the application process***

Across social assistance programmes, a common challenge was the yearly application cycle. Applications not submitted before the one annual deadline must wait an additional year before receiving any allotments. Amongst Disability Allowance recipients in the quantitative survey, almost half (47%) reported waiting over a year between submitting their application to the VDC and receiving their first

payment. Similarly, for recipients of the Old Age Allowance, many are not aware that they need to apply the year before they meet the minimum starting age.

Applications for disability cards presented further challenges. Many people with disabilities and/or their caregivers assisting with the application process reported being unclear on which documents were needed. Even if they had all required documents, many were asked to provide extra medical documentation to complete the assessment, as described above. Furthermore, since the Disability Identification Committee meets infrequently, applicants may face long waiting periods if they are not aware of the schedule. In the quantitative survey, people who had successfully gotten a disability card reported an average of three visits to application points to complete the process.

Lack of clarity on application procedures led to delays or frustration. For example, a father faced many difficulties getting a disability card for his daughter, who is blind and has a hearing impairment. He explained that he needed to go to Pokhara three times and Damauli (district headquarter) four times, as he was told *“this thing or that thing was missing or would not do.”* In certain cases, the process appeared so daunting that it deterred starting or continuing an application altogether.

Finally, people with disabilities, including disability cardholders, and their caregivers were often not clear on how assessments, including card categorisations, were decided. Most people equate the disability card with the Disability Allowance, so frequently expected to get a cash transfer if they are applying for a card. Lack of awareness about the assessment criteria and the benefits attached to each category can lead to resentment and distrust of the process. For example, several respondents felt assessment decisions came down to political connections, such as the father of a man, aged 49, who has mobility and communication impairments. He did not apply for a card as he believes that lack of *afno manchhe* (one's acquaintance in power or position) would be a barrier. This perspective was also mirrored by some of the key informants. For example, some felt that those who are “clever” and literate go to the district and get the type of card they wish, but those who have greater needs often do not get it.

Several provisions were reported to have improved the ease of the application process, particularly for disability-targeted programmes. For example, for all social

assistance programmes, policies are being changed to increase the number of annual deadlines. Additionally, in Tanahun and other districts, the involvement of Disability Identification Committees in disability card assessments is limited to complex cases. Since the Disability Identification Committee meets infrequently and irregularly, key informants noted that having the WCDO, the office where applications are first submitted to, complete most assessments streamlines the process: wait times are decreased and more predictable, which also improves financial accessibility given that many people travel and reside in the district headquarter while their application is processed. Finally, in Tanahun, key informants reported strong involvement of local DPOs, including in guiding applicants through the application process.

### ***Awareness and perceived utility of benefits***

While awareness of the Disability Allowance and other social assistance programmes was generally high, many people with disabilities and their caregivers did not know about benefits such as transportation and healthcare discounts that are available for lower level cardholders.

Additionally, even if people with disabilities or their caregivers were aware of these programmes, many did not perceive them to be useful. This perception was linked to concerns about the quality and availability of services. For example, public transportation is not available in many parts of Nepal and vocational training programmes may not offer relevant skills. Similarly, schools might not have adequate resources to support the learning of children with disabilities. Of note, while scholarships are available to any level cardholder, national level key informants stated that scholarships were not intended for children with the most severe disabilities (red cardholders) as *“they will not be going to school.”*

### ***Compliance among linked service providers***

Particularly for healthcare and transportation discounts, several respondents in the qualitative research reported difficulties accessing benefits at point of use. For example, a 49-year-old woman related that bus drivers scold her when she presents her card for a discount. Similarly, the mother of a man with an intellectual impairment went to the district hospital after hearing about healthcare discounts associated with the disability card. She reported that *“not a drop [of medicine] was given for free”* and

was instead told by a staff member that a *“disability card won’t do anything in the hospital.”*

Key informants attributed poor compliance amongst service providers to lack of awareness of disability card benefits, as well as motivation to maximize profits. To improve awareness, the WCDO runs information sessions with transportation owners’ organisations and other service providers. However, monitoring and enforcement mechanisms to ensure compliance are admitted to be weak.

## **Discussion**

This research measured coverage and uptake of disability-targeted and non-targeted social protection programmes among people with disabilities in Nepal, and explored factors that encourage or impede participation. Evidence in this area has thus far been relatively limited [13], and so this research can help inform planning and delivery of social protection systems to ensure equitable access for people with disabilities.

Few studies have measured social protection enrolment among people with disabilities, in either disability-targeted or non-targeted schemes. Concerning disability-targeted schemes, slightly less than a third of people with disabilities had a disability card and only 13.4% were receiving the Disability Allowance. A small portion (7.7%) of eligible cardholders were not receiving the Disability Allowance, which is significantly lower than the 58% exclusion reported in other areas of Nepal in a survey conducted before the removal of quotas for blue card holders [52]. Overall, coverage of the Disability Allowance is slightly higher than the modelled regional estimate for disability-targeted cash benefits, which is estimated at 9.4% for Asia and the Pacific [4].

Over a third of people with disabilities were receiving some type of social assistance, which was much higher compared to people without disabilities. The Old Age Allowance was the main cash transfer accessed amongst both people with and without disabilities, and had universally high coverage. High coverage of the Old Age Allowance amongst older adults as a group has been reported in other research from other areas of Nepal [41, 53]. This research indicates that older adults with disabilities are accessing this cash transfer in equal proportion to older adults without

disabilities, indicating equity in access. Among older adults eligible for both the Disability Allowance and the Old Age Allowance, there was a clear preference for the Old Age Allowance. The Old Age Allowance currently provides the same amount as the Disability Allowance for red cardholders, although disability cards also provide access to other benefits (e.g. transportation discounts). However, the application process is much more straightforward for the Old Age Allowance: eligibility is relatively easy to assess, applications are conducted in the local VDC and application procedures are straightforward.

In general, disability-targeted schemes in Nepal appear much more challenging for eligible individuals to enrol in than non-targeted schemes. No other schemes require travel to the district headquarter as part of the application process, a requirement that may be particularly onerous for people with disabilities. As people with disabilities are more likely to be living in poverty, meeting the financial costs associated with travel will be more difficult [17]. Similarly, the lack of accessible transportation is particularly disadvantageous to people with mobility limitations or in remote areas. Other research, including in other areas of Nepal [41, 54], has highlighted that geographic and financial factors can be a barrier to accessing social protection among people with disabilities [24, 27, 55, 56]. As many areas of Nepal have even more inaccessible topography compared to Tanahun, such as across the Mountain region, geographic and financial challenges associated with traveling to district headquarters for disability cards will likely be even greater in these regions.

Further, challenges in establishing and applying disability assessment criteria mirror research in other contexts, indicating a widespread challenge in the design and implementation of disability-targeted programmes [23, 27, 55, 57]. At the policy level, Nepal's disability assessment guidelines focus on functioning, which is in line with international conceptualisations of disability [14, 49]. Functioning-based assessments can also be more practical to implement than medical-based protocols due to a lower reliance on specialised resources and expertise [23, 27, 30, 55, 56, 58]. However, evidence from Tanahun and other areas of Nepal suggests implementation does not always follow official guidelines [41]. The majority of applicants reported requiring medical documentation to complete their applications, which was both cumbersome to obtain and moves away from the recommended functioning-based approach to disability assessment. While functioning-based tools



for assessing mental health conditions and some other impairments is a global challenge [59], many other disability types can be effectively captured without medical assessment.

Additionally, universally low coverage of social insurance (e.g. pensions) and social protection benefits other than cash transfers have been reported in other research from LMICs [8]. Social insurance is often limited to the formal sector, which covers a minority of people in most LMICs. For Nepal, 90% of the labour force works in the informal sector and are thus ineligible for social insurance [35]. There is some evidence from other countries that people with disabilities are even more likely to work in the informal sector compared to people without disabilities [20]. Further, women with disabilities are particularly likely to be excluded from social insurance, due to gender as a source of exclusion from employment and greater engagement in unpaid and domestic work [15, 27].

Moreover, the restriction to only receiving one type of social assistance does not account for intersecting dimensions of exclusion [54]. For example, disability and poverty are both more common in older age [13, 60]. Older adults with disabilities will thus have to contend with both disability-related costs as well as the loss of income from retirement from the same the allotment. Older adults with disabilities with inadequate family or social support, such as people without adult children or who are widowed, are particularly vulnerable to poverty [60]. Similarly, single women or widows with disabilities may not be able to cover both daily living costs (if they are not engaged in paid work) on top of disability-related costs from the same allowance. Removing restrictions on the receipt of multiple benefits or varying benefit levels would therefore be more equitable, to account for the multiple sources of vulnerability.

Finally, although this study did not measure the impact of receiving social protection, it is unlikely that in its current state social protection will be sufficient in meeting its intended goals among recipients with disabilities in Nepal, particularly in promoting stronger livelihoods and social inclusion. Integrated poverty reduction programmes, which combine income transfers, investments in human capital and improved access to services are more likely to address chronic poverty and social exclusion compared to pure income transfers [6, 15]. The design of disability-targeted social protection in Nepal has taken this multidimensional approach, by combining the Disability

Allowance with linked benefits to strengthen recipients' capabilities (e.g. vocational training, education scholarships) with interventions to increase access to services (e.g. transportation and healthcare discounts). However, low uptake of these linked benefits, due in part to concerns over their quality, availability and lack of compliance among services providers hampers the effectiveness of these tools. Further, complementary interventions may be needed to address discrimination and marginalisation of disability, as well as of overlapping vulnerabilities (e.g. gender, caste, religion).

Still, despite challenges, it is important to note that several changes to policy and practice appear to have improved access to social protection among people with disabilities in Nepal. For example, funding for all social protection has increased and quotas on the number of Disability Allowance recipients have been removed [35]. Additionally, the involvement of DPOs has increased awareness of disability-targeted programmes, including how to apply. DPOs have been reported to improve understanding of disability among assessors, which may help lead to more equitable classifications. Similarly, outreach camps target financial and geographic barriers to access, as well as improve the ease of the application process. Plans to increase the number of annual deadlines for all social assistance programmes are likely to reduce wait times to receiving payments.

Additional research is needed to explore access to social protection among people with disabilities in other areas in Nepal, as well as other countries globally. In particular, assessing the effectiveness of different tools and procedures for functioning-based disability assessment would be useful for social protection planning and implementation. Additionally, more information is needed on the impact of social protection schemes, particularly against intended aims of poverty reduction, strengthening livelihoods, decreasing inequalities and improving social inclusion [61, 62]. Research in other areas of Nepal indicate a high need for social protection among people with disabilities, as they are more likely to be living in poverty and face inequalities in areas such as access education and work [63, 64], which follows international trends [13, 17]. Research on the impact of social assistance for people living in poverty more broadly indicate a range of potential positive outcomes, including greater investment in human capital and productive assets, protecting minimum standards of living and shifts in the balance of power

household decision-making regarding resource allocation [65-68]. Whether people with disabilities receiving social assistance and other social protection entitlements share similar benefits is less clear.

### **Strengths and limitations**

In interpreting the results of this research, several limitations should be taken into account. Notably, Tanahun was selected to highlight best practices in Nepal's social protection system, and thus may not be reflective of the situation throughout the country. Additionally, the Washington Group questions used to measure disability in the quantitative research may underestimate the prevalence of disability, as they may not capture all forms of functional limitations. For example, certain mental health conditions may not be captured (e.g. bipolar disorder, schizophrenia); however, the experience of people with these types of disabilities was explored through qualitative research.

A major strength of this study is the use of mixed methods. Combining qualitative and quantitative research in presents an opportunity to measure coverage and uptake, while also exploring the underlying factors affecting those figures. Further, mixed methods allowed for triangulation of findings across different respondents and methodologies, which strengthens the validity of key results. Another key strength of this study is that participants were recruited from the general population, which improves the generalisability of results.

### **Conclusion**

Social assistance remains the dominant form of social protection accessed by people with and without disabilities alike in the Tanahun district, with the Old Age Allowance demonstrating universally high coverage. Overall, 37% of people with disabilities were accessing social assistance, which was significantly higher compared to people without disabilities. Few people with or without disabilities were accessing social insurance tied to employment in the formal sector.

Many people with disabilities remain excluded from programmes that they are eligible for. Points of exclusion occurred at different stages of design and delivery of social protection, with some strategies proving effective at promoting greater access.

### *Aligning programme benefits to the needs of people with disabilities*

In their conception, Nepal's disability-targeted programmes take an integrated approach to poverty reduction as they combine a cash transfer (for certain recipients) with other benefits that could help to strengthen livelihoods and well-being [6]. However, the quality and availability of linked services, as well as compliance in honouring them among service providers, led to perceptions that they were not worth applying for or using. Further, although the Disability Allowance and other cash transfers are set to double in value in the 2016/2017 fiscal year, it is unlikely that they will cover the range of expenses that people with disabilities and their households often incur, such as for disability-related costs and loss of income from household members involved in caregiving or from exclusion of people with disabilities from work [22, 23]. Improving the quality and availability of linked services, as well as the value of the cash transfer, will likely improve the impact of these programmes, as well as encourage greater enrolment.

Other programmes take less of a consideration of the needs of people with disabilities in their design. All social assistance programmes offer a set rate for all recipients and an individual can only participate in one programme. Removing restrictions to a single scheme or adapting benefit levels could better address poverty stemming from multiple vulnerabilities [24, 54]. Similarly, social insurance programmes should be broadened to include the informal sector, where the majority of Nepali citizens with and without disabilities work.

### *Awareness of programmes*

Overall, awareness of the Disability Allowance and other cash transfers was high amongst people with disabilities and their caregivers in Tanahun. However, awareness of some of the non-cash benefits was low, as was a clear understanding of application procedures and eligibility requirements. Clear communication strategies on programme availability and eligibility has been highlighted as an important strategy for minimising exclusion, which will require adaptations to reach

people with certain impairments or who are illiterate [24, 56]. The active involvement of DPOs in Tanahun and other areas of Nepal has been a good strategy for spreading knowledge of disability-targeted programmes, including application procedures. However, adoptions to communication strategies for non-targeted programmes may be needed to ensure people with disabilities receive adequate information.

### *Determining eligibility*

Disability-targeted programmes have the most complex assessments of eligibility compared to other social assistance programmes in Nepal. While disability eligibility criteria are in-line with the UNCRPD, administrative capacity is lacking to carry out assessments effectively, which has been reported as a common challenge in other contexts [24, 27, 58, 69]. The involvement of DPOs in assessment committees has been useful in improving understanding of disability, although more rigorous training of assessors is still needed, particularly in areas without a strong DPO presence. Finally, the removal of quotas on Disability Allowances for blue cardholders – which led to a doubling in the number of Disability Allowance recipients – illustrates the high level of exclusion resulting from arbitrarily rationing access.

### *Application procedures*

Disability-targeted programmes had the most cumbersome application procedures compared to other forms of social assistance. A key challenge to enrolling in disability-targeted programmes was the requirement to travel to application offices in district capitals, as well as to gather medical documentation. Further, the infrequency and irregularity of assessment board meetings led to further delays, additional costs and frustrations amongst applicants. Mobile outreach camps are an important innovation in reducing these challenges, which have also been used successfully in other contexts [70]. Additionally, across social assistance programmes, the once annual deadline to register leads to long delays – and potential worsening of poverty and exclusion in the interim [24]. The proposal to increase the number of annual registration deadlines across programmes is a positive change, which will likely improve access as well as impact.

## Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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## ***Chapter 8. Adequacy of social protection amongst people with disabilities in Cam Le, Vietnam and Tanahun, Nepal***

*Chapter 6, Paper 3* highlighted that people with disabilities in both Cam Le, Vietnam and Tanahun, Nepal face high levels of monetary and multidimensional poverty, as well as inequalities compared to people without disabilities. These findings indicate an increased need for social protection amongst people with disabilities to alleviate poverty and improve well-being.

*Chapter 7, Papers 4 & 5* in turn found many people with disabilities, as well as people without disabilities, were accessing social protection programmes – namely social assistance – in both settings. In Cam Le, Vietnam, 52.7% of people with disabilities were receiving any type of social assistance, while in Tanahun, Nepal, 36.8% were recipients. In comparison, 11.7% and 21.1% of people without disabilities in the case-control study were social assistance recipients, in Vietnam and Nepal respectively.

Although social protection is promoted as a critical tool for alleviating poverty “in all its forms”, little research has explored the adequacy of social protection in meeting its intended aims among people with disabilities, who are considered a key target group in both national and international social protection strategies [1-3]. Filling this gap in knowledge is particularly important for social assistance, which is the dominant form of social protection in LMICs [4]. Overall, 170 countries globally have implemented state-sponsored, disability-targeted periodic cash benefits [5]. In Asia and the Pacific, 9.4% of people with severe disabilities were estimated to be accessing disability-targeted social assistance in modelled approaches [5]. Additionally, people with disabilities may also be included in other programmes, for example, those targeted to older adults [5]. As revealed in *Chapter 6, Paper 2*, however, little is known on whether participation in these programme is sufficient to ensure people with disabilities and their households are protected from different forms of poverty [6].

Consequently, this chapter explores whether participation in social protection programmes – namely social assistance – adequately meets its intended aims of alleviating monetary and multidimensional poverty, and reducing inequalities.

## 8.1 Methods

Respondents in both settings (Cam Le in Vietnam, Tanahun in Nepal) were people with and without disabilities, aged 15 and older, who were recruited through the population-based surveys and participated in the case-control studies (methods described in detail in Chapters 6 and 7).

Social assistance recipients were defined as people currently receiving a regular cash transfer provided by the government. Social protection programmes operating in the study districts are outlined in Table 1. As described in *Chapter 6, Papers 3 & 4*, all cash transfers are unconditional. An individual can only receive one cash transfer at a time, with the exception the Single Parents' Allowance in Vietnam. Monthly amounts provided range from NPR 200-1000 (US\$8.12-40.60, 2011 PPP) in Nepal to VND 270,000-2,700,000 (US\$40.24-402.38, 2011 PPP) in Vietnam. Several cash transfers also have other linked benefits, although analyses did not account for their uptake.

Monetary and multidimensional poverty amongst respondents were measured using similar approaches as described in the methods of *Chapter 6, Paper 3*. Indicators included:

- Monetary poverty headcount and poverty gap using national poverty lines
- Monetary poverty headcount and poverty gap using national poverty lines, adjusted for disability-related extra costs
- Multidimensional poverty headcount (H), intensity (A) and adjusted headcount (MPI)

Monetary poverty was defined using national poverty lines in Vietnam and Nepal (VND 780,000 per person per month in Vietnam, equivalent to \$3.82 per person per day, 2011 PPP; NPR 19,261 per person per year in Nepal, equivalent to \$2.14 per person per day, 2011 PPP). These poverty lines were raised by the estimated extra costs of disability, which were calculated in *Chapter 6, Paper 3* using the Standard of Living [7] approach as 74.7% and 29.4% of household income in Vietnam and Nepal, respectively. These adjusted national poverty lines were equivalent to \$6.67 (Vietnam) and \$2.77 (Nepal) per person per day, 2011 PPP. For multidimensional

**Table 1. Social assistance programmes in Nepal and Vietnam**

<b>Programme</b>	<b>Eligibility</b>	<b>Amount (per month)</b>	<b>Linked benefits</b>
<i>Vietnam</i>			
Disability Allowance	People assessed as having a severe or extremely severe disability	VND 405,000 [\$60] <sup>15</sup> (severe) VND 540,000 [\$80] (extremely severe; severe if child or older adult) VND 670,000 [\$100] (extremely severe, child or older adult)	Health insurance, education supports, vocational training & employment supports, transport discounts
Old Age Allowance	People aged 80+ (with no pension) or aged 60+ and below the poverty line	VND 270,000 [\$40] (people aged 60-79 and under poverty line; people aged 80+ not in poverty, but with no pension) VND 540,000 [\$80] (people aged 80+ under the poverty line)	Health insurance
Single Parents Allowance	Unmarried/widowed parent in households below the poverty line raising a child (<16 years, or 16-22 if child is in school)	VND 270,000 [\$40] (1 child), VND 540,000 [\$80] (2+ children)	Health insurance (for children)
War Contributors, Victims of Agent Orange	Veterans of war with US or their family members who developed disabilities/illness due to Agent Orange exposure	Variable (VND 1,479,000–3,609,000) <sup>16</sup> [\$220-537]	Health insurance
<i>Nepal</i>			
Disability Allowance	People with disabilities who hold a red or blue disability card	NPR 1000 [\$41] (red), NPR 300 (blue) [\$12]	Healthcare discounts, education supports, vocational training & employment supports, transportation discounts
Old Age Allowance	People aged 70+ or 60+ if members of Dalit caste	NPR 1000 [\$41]	Healthcare discounts
Single Women's Allowance	Single women aged 60+ years or widows of any age	NPR 500 [\$20]	None
Child's grant	Parents of children under 4 years who are poor and Dalit caste	NPR 200 (one child) [\$8] NPR 400 (2+ children) [\$16]	None

poverty, the same MPI structure as reported in *Chapter 6, Paper 3* was used, as was the poverty cut-off of  $k \geq 30$ .

Multivariate regression was used to compare indicators of monetary and multidimensional poverty between social assistance recipients with disabilities and (a) people with disabilities not receiving social assistance, (b) people without disabilities receiving social assistance, and (c) people without disabilities not receiving social assistance. Regression analyses were adjusted for the individual's age and gender and the household's location (rural/urban for Nepal, ward number for Vietnam).

## 8.2 Results

### ***Monetary poverty***

Amongst people with disabilities in Nepal, social assistance recipients were more likely than non-recipients to be living below the national poverty line (20% vs 6.7%) (Table 2). Both groups faced similar poverty gaps, equivalent to about a third of the poverty line. The poverty headcount then rose by 5.3% for social assistance recipients (to 25.3%) and by 8.4% for non-recipients (to 15.1%) when the poverty line was adjusted for disability-related extra costs. With this adjustment, the difference in the poverty headcount between groups was no longer significant. However, the difference in the poverty gap widened, so that recipients experienced a higher intensity of poverty than non-recipients.

Social assistance recipients with disabilities in Nepal were also more likely to live below both the adjusted and unadjusted national poverty line compared to people without disabilities; however, this difference was only significant when compared to non-recipients without disabilities. There were no differences in the poverty gap between recipients with disabilities and people without disabilities.

Turning to Vietnam, there were no significant differences in the unadjusted monetary poverty headcount amongst people with disabilities when comparing recipients and non-recipients. However, non-recipients with disabilities had a higher poverty headcount at the adjusted poverty line than recipients with disabilities (46.2% vs

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<sup>15</sup> All dollar amounts are 2011 PPP.

<sup>16</sup> Highest reported amount received in study sample was VND 2,700,000 per month

32.8%). There was no difference in poverty gap between recipients and non-recipients with disabilities at either the adjusted or non-adjusted poverty lines.

Non-disabled recipients had the highest poverty headcount at the unadjusted poverty line of any group in Vietnam (33.3%); however, this difference was not statistically significant when compared to social assistance recipients with disabilities. Overall, there were also no significant differences in poverty headcount or gap between disabled recipients and people without disabilities (recipients or non-recipients) at the unadjusted poverty line. At the adjusted poverty line, however, disabled recipients were significantly more likely to be poor compared to non-disabled recipients.

### ***Multidimensional poverty***

In Nepal, there was no difference in multidimensional poverty amongst people with disabilities when comparing recipients and non-recipients (Table 2). Slightly over half of people with disabilities in each group were multidimensionally poor and experienced an intensity of poverty equivalent to 40% of weighted deprivations. There were also few significant differences between recipients and non-recipients with disabilities on individual indicators. However, non-recipients were more likely to be deprived on the indicator for work and old age security than recipients (58.0% vs 29.3%, respectively) and household overcrowding (26.1% vs 12.0%).

Social assistance recipients with disabilities in Nepal were much more likely to multidimensionally poor compared to both recipients and non-recipients without disabilities (23.3% and 26.7% respectively, compared to 56.0% for disabled recipients). Social assistance recipients with disabilities also experienced a higher intensity of poverty compared to non-recipients without disabilities (41.1% vs 37.2%). On individual indicators, social assistance recipients with disabilities were more likely to be deprived in voting, decision-making and experience violence in comparison to people without disabilities (both non-recipients and recipients). Recipients with disabilities were also more likely to be deprived on the indicator for work and old age security, but less likely to be deprived on the indicator for cooking fuel, compared to recipients without disabilities. Further, recipients with disabilities were more likely to be deprived on the sanitation and asset indicators compared to non-recipients without disabilities.

**Table 2. Monetary and multidimensional poverty by receipt of social assistance and disability status**

	Tanahun, Nepal			Cam Le, Vietnam		
	People with disabilities		People without disabilities	People with disabilities		People without disabilities
	Social assistance (n=75)	No social assistance (n=119)	Social assistance (n=43)	No social assistance (n=150)	Social assistance (n=73)	No social assistance (n=65)
<b>MONETARY POVERTY</b>						
<i>Unadjusted national poverty line<sup>§</sup></i>						
Poverty headcount	20.0%	6.7%*	11.6%	8.0%**	11.0%	20.0%
Poverty gap	31.7%	30.0%	43.7%	32.1%	40.3%	35.0%
<i>Adjusted national poverty line*</i>						
Poverty headcount	25.3%	15.1%	11.6%	8.0%**	32.8%	46.2%*
Poverty gap	40.4%	27.4%*	43.7%	32.1%	36.2%	41.6%
<b>MULTIDIMENSIONAL POVERTY</b>						
Poverty headcount (H)	56.0%	58.8%	23.3%**	26.7%***	46.6%	44.6%
Intensity of poverty (A)	41.1%	42.7%	37.2%	37.2%*	35.2%	37.1%
Adjusted headcount (MPI)	0.230	0.251	0.086***	0.099***	0.164	0.165
<i>Individual indicators (all % deprived)</i>						
Work	29.3%	58.0%**	7.0%**	34.0%	60.3%	72.3%
Food security	5.3%	16.8%	11.6%	5.3%	6.9%	6.2%
Voting	30.7%	25.2%	9.3%*	17.3%*	50.7%	38.5%
Decision-making	24.0%	18.5%	0.0%***	2.0%**	43.8%	38.5%
Water	60.0%	58.8%	48.8%	56.0%	9.6%	13.9%
Sanitation	45.3%	34.5%	48.8%	22.7%***	5.5%	3.1%
Healthcare spending	22.7%	24.4%	14.0%	16.0%	15.1%	27.7%*
Health event	14.7%	16.8%	16.3%	11.3%	37.0%	35.4%
Violence	16.0%	12.6%	0.0%**	4.0%**	5.5%	7.7%
Cooking fuel	81.3%	81.5%	93.0%*	80.0%	6.9%	4.6%
Flooring	73.3%	73.1%	76.7%	60.0%	1.4%	3.1%
Overcrowding	12.0%	26.1%*	16.3%	20.0%	17.8%	30.8%
Assets	42.7%	37.8%	48.8%	22.7%*	2.7%	0.0%

<sup>§</sup>National poverty line is VND 780,000 per person per month in Vietnam (equivalent to \$3.82 per person per day, PPP) and NPR 19,261 per person per year in Nepal (equivalent to \$2.14 per person per day, PPP). \* Adjusted national poverty lines are VND 1,363,000 per person per month (equivalent to about \$6.67 per person per day, PPP) and NPR 24,924 per person per year (\$2.77 per person per day, PPP); Statistical significance in multivariate analysis (adjusted for age, sex and location), all comparisons to social assistance recipients with disabilities: \*p<0.05, p<0.01, p<0.001

In Vietnam, there was also no difference in multidimensional poverty between recipients and non-recipients with disabilities. The multidimensional poverty headcount was similar for both groups (46.6% for recipients vs 44.6% for non-recipients), as was the intensity of poverty (35.2% vs 37.1%) and the MPI (0.164 vs 0.165). There was also no significant difference on any of the individual indicators, although non-recipients were more likely to face impoverishing spending (27.7% vs 15.1%,  $p=0.06$ )

However, social assistance recipients with disabilities in Vietnam were much more likely to be multidimensionally poor compared to both recipients (0.0%) and non-recipients (2.5%) without disabilities and thus experienced a higher MPI. On individual indicators, recipients with disabilities were more likely to be deprived in work and old age security, voting, decision-making, access to clear water, having a negative health event and violence compared to both non-recipients and recipients without disabilities.

### **8.3 Discussion**

Overall, evidence from Cam Le, Vietnam and Tanahun, Nepal indicate that social assistance – in its current state – is insufficient to protect many recipients with disabilities from either monetary or multidimensional poverty. Notably, a quarter to a third of social assistance recipients with disabilities were living below the adjusted poverty lines (25.3% in Nepal and 32.8% in Vietnam) and around half of social assistance recipients with disabilities in both settings were living in multidimensional poverty (56.0% in Nepal and 46.6% in Vietnam). People with disabilities were significantly more likely to be living in poverty compared to people without disabilities (non-recipients without disabilities), indicating social exclusion.

Further, people with disabilities who were not receiving social assistance also experienced high levels of poverty, particularly multidimensional poverty, indicating an unmet need for social protection across the population. Amongst people with disabilities in Nepal, non-recipients were less likely than recipients to be living in poverty; however, the proportion of non-recipients living in poverty more than doubled at the adjusted poverty line, indicating many are living close to but slightly over the national poverty line. In Vietnam, non-recipients with disabilities were even more likely to be living in monetary poverty at the adjusted poverty line compared to



recipients with disabilities – potentially indicating a protective effect of social assistance on monetary poverty. Additionally, non-recipients with disabilities experienced high levels of multidimensional poverty, equivalent to recipients with disabilities, in both settings (58.8% in Nepal and 44.6% in Vietnam).

In Vietnam, social assistance recipients without disabilities also experienced high levels of monetary poverty, which may reflect that most non-disability targeted programmes are means-tested [8]. Although a third of social assistance recipients without disabilities were living in monetary poverty, none were multidimensionally poor. This finding indicates different poverty profiles amongst social assistance recipients with and without disabilities, which has implications for the design and delivery of social protection. For both groups, social assistance needs to be strengthened to reduce monetary poverty amongst recipients; however, social assistance and other social protection activities also need to target drivers of multidimensional poverty amongst recipients with disabilities, such as social exclusion.

Other research exploring the adequacy of social protection amongst people with disabilities in LMICs is lacking. However, available evidence has reinforced the insufficiency of social protection in protecting people with disabilities against poverty. For example, studies from South Africa and China found that while social assistance may help households in meeting basic needs, it was insufficient in providing a long-term escape from poverty [9-11]. One study from Namibia indicated that disability-targeted social assistance significantly reduced people with disabilities' likelihood of living in a monetary poor household, although authors' estimated through modelling approaches that the cash transfers were unlikely to reduce high levels of inequality [12]. Further, some studies have found little effect of social protection receipt on multidimensional indicators of poverty, such as healthcare access [13, 14], or even negative effects in areas such as employment and mental health [15, 16].

Social protection may have been inadequate to protect against poverty amongst people with disabilities for a number of reasons, namely (a) the insufficient value of cash transfers, (b) design and delivery of linked benefits, (c) lack of autonomy in decision-making and (d) barriers to inclusion in society.

### ***Insufficient value of cash transfers***

The income received through cash transfers is unlikely to be adequate to push most disabled households out of poverty, let alone support extra disability-related costs. For example, the Disability Allowance and the Old Age Allowance were the most frequently accessed programmes – and had the highest monetary value – amongst social assistant recipients with disabilities in Nepal. At the time of this study, the maximum amount provided was NPR 1000 (US\$41, 2011 PPP) per month, which was expected to rise to NPR 2000 (US\$81, 2011 PPP) per month in the 2016/2017 fiscal year [17]. However, extra costs related to disability were estimated at over NPR 6000 (US\$243, 2011 PPP) per month and the household shortfall in reaching the unadjusted poverty line amongst social assistance recipients with disabilities was on average NPR 2180 (US\$88) per month. Consequently, even the increased value of the Disability Allowance would be insufficient to push most disabled households across the unadjusted poverty line, let alone cover any disability-related extra costs.

Similarly, in Vietnam, extra costs related to disability were estimated at 4.4 million VND (US\$656, 2011 PPP) per month and the average shortfall in reaching the unadjusted poverty line amongst households with social assistance recipients with disabilities was 2.6 million VND (US\$393, 2011 PPP) per month. Most social assistance recipients were receiving the Disability Allowance or the Old Age Allowance, which provided a maximum of VND 670,000 (US\$100) per month. Even the cash transfers for War Veterans and Victims of Agent Orange – which provide substantially higher amounts (up to 3.6 million VND, or US\$537 in 2011 PPP) – would be insufficient on its own to cover both shortfalls in reaching the poverty line and extra disability-related costs. Further, only a few respondents with disabilities accessed these cash transfers (n=7; 5%).

The insufficient value of many cash transfers has been highlighted in research and advocacy from Vietnam and Nepal. For example, a review of Vietnam's social protection strategy by the International Labour Organisation recommended an increase to the value of the Disability Allowance [18]. Additionally, a study in Nepal estimated that cash transfers only push about 0.4% of all recipients (with and without disabilities) out of poverty [19]. The inadequacy of cash transfers in both ensuring people with disabilities have enough income to meet basic needs and covering disability-related extra costs has also been illustrated in other contexts [5, 20].

### ***Challenges in the design and administration of linked benefits***

Other benefits linked to social assistance may provide in-kind coverage for many expenses, reducing the need for cash transfers [5]. For example, the Disability Allowance, which was one of the main forms of social assistance accessed by people with disabilities in both settings, provides a range of linked benefits (e.g. health insurance/health discounts, subsidised transportation, supports to improve access to education and employment). Further, all social assistance recipients in Vietnam receive state-subsidised health insurance.

However, findings from *Chapter 6, Paper 3* indicate that uptake of these benefits, apart from health insurance in Vietnam, was low amongst recipients. Many people did not use these benefits due to lack of awareness or perceptions of low utility. For example, vocational training courses was reported to not provide users with employable skills based on their skill sets and the demands of the local economy. Additionally, in Nepal, recipients reported difficulties using some benefits due to poor compliance among service providers. For example, bus drivers or hospital staff would frequently not honour Disability Allowance recipients' discounts for subsidised transport or healthcare services.

Further, linked benefits were not always aligned with needs of people with disabilities. For example, health insurance in Vietnam only covered a small subset of required rehabilitation services and rarely covered assistive devices [21, 22]. Rehabilitation, assistive devices and other specialised healthcare have consistently been identified as a large source of disability-related extra costs [14, 20, 22-24]. Their exclusion from health insurance coverage likely increases out-of-pocket spending or leads to lower levels of health, functioning, and well-being if costs can't be met. Indeed, 15% of social assistance recipients with disabilities in Vietnam still experienced impoverished healthcare spending, although this was less than that experienced by non-recipients with disabilities (27.7%), who would not have had state-subsidised health insurance. Lack of coverage of disability-related healthcare costs in health insurance likely decreases the effectiveness of social protection in protecting against poverty amongst people with disabilities.

### ***Lack of autonomy in decision-making***

A key aim of social protection is to promote greater agency and social inclusion of people living in poverty and facing other forms of marginalisation [25-27]. Autonomy and self-determination are also at the core of the UNCRPD [28]. However, social assistance recipients with disabilities in Vietnam and Nepal faced high levels of deprivation on multidimensional poverty indicators related to social participation (e.g. decision-making in the household, voting), which were significantly higher compared to both social assistance recipients and non-recipients without disabilities. Further, in a survey of Disability Allowance recipients, 39% and 38% of respondents aged 15+ in Nepal and Vietnam, respectively, reported that they had no input into how the cash transfer was spent.

These findings may reflect concerns that social protection programmes can reinforce, rather than combat, a charity model of disability, in which people with disabilities are seen as dependant and incapable of making choices about their own lives [29]. Under a more transformative approach, social protection should serve as a tool to promote equity and social justice, by empowering and protecting the rights of people with disabilities, including the right to independent living and self-determination [25, 29, 30]. It is therefore unlikely that social protection will be transformative for people with disabilities if a large proportion of recipients have no control over how their entitlements are used and continue to face social exclusion within and outside the household.

### ***Barriers to inclusion in society***

Cash transfers, as well as many linked benefits (e.g. transportation discounts, healthcare subsidies/health insurance, educational scholarships), can target sources of extra costs and thereby reduce monetary and multidimensional poverty. However, these entitlements primarily address financial barriers to improving well-being. For example, cash transfers or health insurance can improve an individual's ability to pay for health services, while educational scholarships reduce the burden of school fees and other costs. Yet people with disabilities may face additional non-financial challenges in accessing needed services, participating in family and community life and developing stronger livelihoods [31-33]. Non-financial barriers may include negative attitudes and discrimination towards people with disabilities, low availability of needed services, inaccessible built environments and lack of adapted

communication. For example, people with disabilities may not access needed healthcare even if they have health insurance or a cash transfer, if the services they require are not available in their area, the health facilities are physically inaccessible, staff are discriminatory or information is not provided to them in their preferred methods of communication. Others have also noted that failure to target drivers of social exclusion (e.g. negative attitudes) will likely limit the effectiveness of social protection, including for people with disabilities [26, 33, 34].

*Chapter 7, Papers 4 & 5* revealed that some of the benefits linked to the Disability Allowances in both Vietnam and Nepal were not used by many respondents due to this lack of broader disability-inclusive planning. For example, Disability Allowance recipients in both settings were entitled to discounts when using public transportation; however, public transportation was not available in many areas and was often inaccessible to people with mobility limitations. Further, schools were reported to rarely have adequate resources to support the learning of children with disabilities (e.g. instruction in sign language, Braille texts). Complementary interventions to reduce these non-financial barriers are therefore needed to maximise the effectiveness of social protection systems. Interventions could include improving the availability and accessibility of linked services (e.g. public transportation, health services, schools), conducting sensitisation campaigns to increase understanding and acceptance of disability and strengthening legislation to better protect the rights of people with disabilities.

### ***Strengths and limitations***

As this study was cross-sectional, we were not able to assess the impact of participation in programmes, so it is possible that social assistance recipients still experienced an improvement in well-being from participation. However, given the high levels of monetary and multidimensional poverty among social assistance recipients with disabilities, it is clear that existing programmes are insufficient on their own to protect many people with disabilities against poverty and promote their full inclusion in society. Complementary qualitative research amongst Disability Allowance recipients in both settings – which was not presented as part of this thesis – also indicated that respondents perceived the cash transfers to have minimal impact in meeting basic needs and developing stronger livelihoods [35, 36].

Additionally, findings may not be generalizable to other areas of Vietnam and Nepal, as the districts of Cam Le and Tanahun were selected for having relatively well-functioning social protection systems and decent availability of disability-related supports. However, given this selection criteria, it is likely that social assistance and linked benefits are less or, at most, equally effective at protecting people with disabilities from poverty in other areas compared to the study settings.

Finally, assessments of adequacy did not account for uptake of linked of benefits as there was insufficient levels of variation (e.g. near universal uptake of health insurance in Vietnam, low uptake of other benefits in both settings) amongst respondents for adequately powered analyses. However, as highlighted in the qualitative research in *Chapter 7, Paper 4 & 5*, there are several issues with their design and administration, which are likely to limit their effectiveness. Assessments also did not take into account the length of time recipients had been receiving benefits. However, in Nepal, all but three social assistance recipients had been receiving cash transfers for at least a year, with remainder enrolled for at least 6 months (given the once annual deadline – see *Paper 5*). Similarly, in Vietnam only nine social assistance recipients (9.5%) had been receiving social assistance for less than six months. Consequently, the majority of respondents would have been receiving entitlements over a sufficient time period to observe an effect.

Still, this research is one of the few assessments of adequacy of any form of social protection amongst people with disabilities in LMICs [6]. It also draws from data collected through population-based surveys, improving the reliability and generalisability of findings. Further, it assesses adequacy of social assistance across both monetary and multidimensional poverty domains, which provides a more holistic understanding of programme effectiveness, and potential areas for further policy and programmatic improvements.

## **8.4 Conclusion**

This research provides clear evidence that social assistance are currently insufficient to protect people with disabilities in Cam Le, Vietnam and Tanahun, Nepal from poverty “in all its forms”. Levels of both monetary and multidimensional poverty were high amongst social assistance recipients with disabilities. Social assistance

recipients without disabilities also experienced high levels of monetary poverty, indicating universal adequacy challenges; however, people with disabilities fared worse, particularly for multidimensional poverty. Further, people with disabilities not receiving social assistance also experienced high levels of poverty, highlighting an unmet need for social assistance and other poverty alleviation efforts.

These findings carry implications for the design and delivery of social protection systems. Notably, the value of the cash transfer, and the content of linked benefits, should better address additional disability-related costs. Further, complementary interventions to promote inclusion of people with disabilities within the household and across all aspects of society are needed to ensure social protection meets its intended aims among recipients with disabilities.

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## SECTION D      DISCUSSION



*Photo: Young girl with a visual impairment in Nepal*

## **Chapter 9. Summary of findings and their implications for disability-inclusive social protection**

Social protection programmes are increasingly being implemented by governments in LMICs to ensure their citizens are protected from poverty “in all its forms” [1]. People with disabilities are often listed as key target groups in national and international social protection frameworks, policies and programmes due to high levels of poverty and social, economic and cultural exclusion [2, 3]. Further, the right to inclusion is established in many international treaties, such as the Universal Declaration of Human Rights (Articles 22 and 25) and the UNCRPD (Article 28) [4, 5]. However, the 2015 annual report of the UN Special Rapporteur on the rights of persons with disabilities highlighted the limited availability of research on social protection and disability, particularly in LMICs [6].

This thesis sought to contribute towards the evidence base on disability, poverty and social protection. The overall aim of this thesis was to explore need for and access to social protection amongst people with disabilities, as well as evaluate the extent to which existing programmes meet the needs of people with disabilities.

### **9.1 Summary**

#### ***Need for social protection***

Social protection programmes aim to protect people from poverty, risk and vulnerability across the life-course [1]. The UN Special Rapporteur on the rights of persons with disabilities further highlights that social protection should serve as a tool for guaranteeing basic income security, promoting access to services, developing stronger livelihoods and achieving full and effective participation of people with disabilities in society [6].

The research contained in this thesis demonstrates a high level of need for social protection amongst people with disabilities. The systematic review on disability and economic poverty (*Chapter 4, Paper 1*) found people with disabilities were more likely to be poor compared to people without disabilities. Overall, 80% of 150 studies found evidence that people with disabilities were significantly poorer compared to people without disabilities. The relationship between disability and poverty was

consistent across impairment types, regions and poverty measures. The proportion of studies finding a positive association between disability and poverty increased by country income level (59% for low income, 67% for lower-middle income, 72% for upper-middle income countries), which may support the theory that as countries develop people with disabilities are more likely to be left behind from progress [7]. Studies of working-age adults with disabilities were also more likely to find an association with poverty compared to studies of older adults (86% vs. 69%).

The need for social protection amongst people with disabilities was further reinforced in the case studies in Cam Le, Vietnam and Tanahun, Nepal (*Chapter 6, Paper 3*). Levels of both monetary and multidimensional poverty were high amongst people with disabilities, and people with disabilities were consistently poorer than people without disabilities across measures. For example, 11.0% and 16.8% of disabled households were living below the national poverty lines in Nepal and Vietnam, respectively, compared to 6.6% and 5.8% of non-disabled households. Further, estimated levels of disability-related extra costs were high, equivalent to 74.7% (Vietnam) and 29.4% (Nepal) of household income. Incorporating these additional costs led to significant increases in poverty rates amongst disabled households: poverty rose from 11.0% to 18.2% in Nepal and from 16.8% to 40.2% in Vietnam. Further, people with disabilities experienced high levels of multidimensional poverty (57.7% and 45.7% in Nepal and Vietnam, respectively, compared to 25.9% and 2.2% amongst people without disabilities). Disparities between people with and without disabilities were particularly pronounced for deprivations in indicators for social inclusion, violence and work/old age security. Disability severity and having functional limitations affecting self-care and cognition were associated with an increased likelihood of being multidimensionally poor in both settings.

### ***Access to social protection***

The systematic review on social protection included eight studies that assessed access to social protection schemes – which were primarily disability-targeted cash transfers – amongst people with disabilities in LMICs. Only three studies used quantitative measures to gauge access, with all finding high levels of exclusion of people with disabilities from programmes for which they were eligible [8-10]. For example, 66-88% of eligible people with disabilities in Vietnam were not enrolled in

health insurance, based on data from the 2001-2002 Vietnam National Health Survey [9], while 42% of people with disabilities were not receiving the Disability Allowance in South Africa in 2003 [8]. No study in the review evaluated participation across all available social protection benefits in the study setting, or provided estimates of equity in coverage either amongst people with disabilities or in relation to people without disabilities.

Other studies included in the review explored barriers to accessing social protection (mainly disability-targeted schemes). The most commonly cited barrier centred on the disability assessment process, which was deemed to be subjective and lead to the exclusion of people with certain types of disabilities, particularly people with more moderate and less visible impairments. Other studies also highlighted issues such as the lack of awareness of available programmes and their application requirements, physical inaccessibility of application points and high costs associated with applying (e.g. for transport, taking time off work).

In the case studies, 52.7% and 36.8% of people with disabilities in Cam Le, Vietnam and Tanhun, Nepal, respectively, were accessing any form of social assistance. People with disabilities were significantly more likely than people without disabilities to be receiving social assistance (Vietnam: aOR 9.6, 95% CI 5.6-16.5; Nepal: aOR 3.0, 95% CI: 1.6-5.3). In Vietnam, the main type of social assistance accessed by people with disabilities was the Disability Allowance (73%), while in Nepal, the Old Age Allowance was the most common (53%). In Vietnam, almost all people with and without disabilities had health insurance, although coverage was slightly higher amongst people with disabilities (96.0% vs 88.3%, aOR: 2.9, 95% CI: 1.1-7.2). In both settings, access to social insurance was low, as was uptake of benefits linked to Disability Allowances.

Research in Vietnam and Nepal also revealed several factors in the design and implementation of social protection programmes that affected access for people with disabilities. Notably, and as reflected in the systematic review, the disability assessment procedures impacted access to disability-targeted schemes. In both settings, disability assessments had been recently updated to reflect definitions of disability more in line with the UNCRPD (i.e. functioning-based rather than impairment-based) and were designed to be implemented by non-medical

professionals. These changes were noted to have improved the capacity of states to conduct assessments, particularly in resource-poor areas of the country, which had led to marked increases in enrolment. However, some challenges still remained. In Nepal, assessment criteria were considered vague and administrators lacked sufficient training in their implementation. Consequently, many applicants were asked to provide medical documentation of their impairments, which led to high costs for applicants and moved away from a UNCRPD-compatible definition of disability. In contrast, eligibility criteria in Vietnam were more objective and most assessments could be conducted without medical expertise. Still, the criteria in the assessment tool focused disproportionately on physical functioning and self-care, which could lead to the exclusion of people with certain impairments, such as psychosocial and hearing impairments. In both settings, DPOs were credited with improving understanding of disability amongst many assessment bodies, which were reported to improve the quality of their assessments.

Low awareness of available programmes and their eligibility criteria were frequently reported barriers to accessing social protection. Another concern was the indirect and opportunity costs incurred when completing applications. Costs were particularly pronounced for disability card applicants in Nepal, who had to travel to district capitals to make their application. In contrast, other social assistance applications were conducted in the more local VDCs. The combination of cost, long travel distances and complex and poorly understood application procedures may explain the preference for the Old Age Allowance over the Disability Allowance amongst people with disabilities who were eligible for both programmes. In contrast, applications for the Disability Allowance and other forms of social assistance in Vietnam were all conducted at People's Committees, the lowest and most local administration unit, which greatly improved geographic and financial accessibility for many applicants. Still, some applicants in Vietnam had to travel to provincial capitals if the local assessment body couldn't make a determination of their eligibility, or if an applicant wished to appeal an assessment decision. Children under six and people with psychosocial impairments were reported to frequently have to travel to provincial capitals, as assessors often faced challenges making disability determinations for these groups.

Additionally, some people with disabilities did not apply for programmes they were eligible for because the benefits were perceived to be low quality or not useful. This perception was particularly common for non-cash benefits, such as entitlements given to people with “mild” disabilities in Vietnam or lower level disability cardholders in Nepal. Concerns over quality in some cases were attributed to the lack of disability-inclusive planning in linked services. For example, public transportation was not available in many areas and was rarely accessible to people with mobility limitations. Additionally, in Nepal, some people were unable to access their benefits at point-of-use, due to poor compliance amongst providers at linked services. For example, bus drivers and hospital staff were reported to refuse to honour the discounts for transportation and health services given to disability cardholders.

### ***Adequacy of social protection***

The systematic review on social protection and disability in LMICs found little robust evidence evaluating the impact or adequacy of social protection amongst recipients with disabilities. Further, most studies focused narrowly on the role of social protection in meeting basic needs or reducing monetary poverty, with only a few exploring more multidimensional indicators of poverty (e.g. access to healthcare, employment, mental health). Additionally, only one study compared impact between people with and without disabilities [11], which is important for evaluating equity.

Still, available evidence from the review suggests that social protection may help people with disabilities and their households meet basic needs; however, it is insufficient in many contexts in helping people with disabilities develop stronger livelihoods and escape poverty. The failure of social protection schemes to adequately cover disability-related expenses was cited by some studies in the review as a potential reason for their limited impact [11-13]. For example, health insurance did not cover many essential health services for people with disabilities in studies from Vietnam and China [9, 13]. Some studies in the review also found negative impacts of social protection. For example, eligibility criteria attached to cash transfers could be deter recipients from working for fear of losing their benefits [14]. Additionally, receiving social assistance could lead to stigma [15] or emotional distress over fear of losing benefits [12].

Research conducted in Cam Le, Vietnam and Tanahun, Nepal further reinforced the inadequacy of social protection programmes in meeting many of their intended aims amongst people with disabilities. For example, 20% of social assistance recipients with disabilities in Nepal and 11% of social assistance recipients in Vietnam were living below the national poverty line. In Nepal, social assistance recipients with disabilities were significantly more likely to be living below the national poverty line compared to non-recipients with and without disabilities, although there was no significant difference compared to recipients without disabilities. In Vietnam, social assistance recipients with disabilities were less likely to be living below the national poverty line compared to recipients without disabilities and non-recipients with disabilities, but this difference was not statistically significant. Further, once poverty lines were adjusted for disability-related extra costs, the proportion of social assistance recipients with disabilities living in poverty rose to 25% in Nepal and 33% in Vietnam. Non-recipients with disabilities were more likely to be living in poverty (46%) in Vietnam – potentially indicating a positive effect of social assistance receipt, as well as an unmet need for intervention amongst non-recipients. Still, over a third of recipients were living in poverty, indicating that social assistance is inadequate at protecting many recipients with disabilities from poverty.

Social assistance appears even less sufficient at preventing multidimensional poverty than monetary poverty amongst people with disabilities. In both Nepal and Vietnam, approximately half of recipients (and non-recipients) with disabilities were multidimensionally poor. Large differences in multidimensional poverty between recipients with and without disabilities were also observed. For example, in Nepal recipients with disabilities had more than twice the MPI score as recipients without disabilities, while in Vietnam no social assistance recipients without disabilities were multidimensionally poor. Deprivations in indicators for social inclusion (voting, decision-making), violence and work and old age security were largely responsible for the high inequalities in multidimensional poverty between recipients with and without disabilities.

## **9.2 Implications of findings**

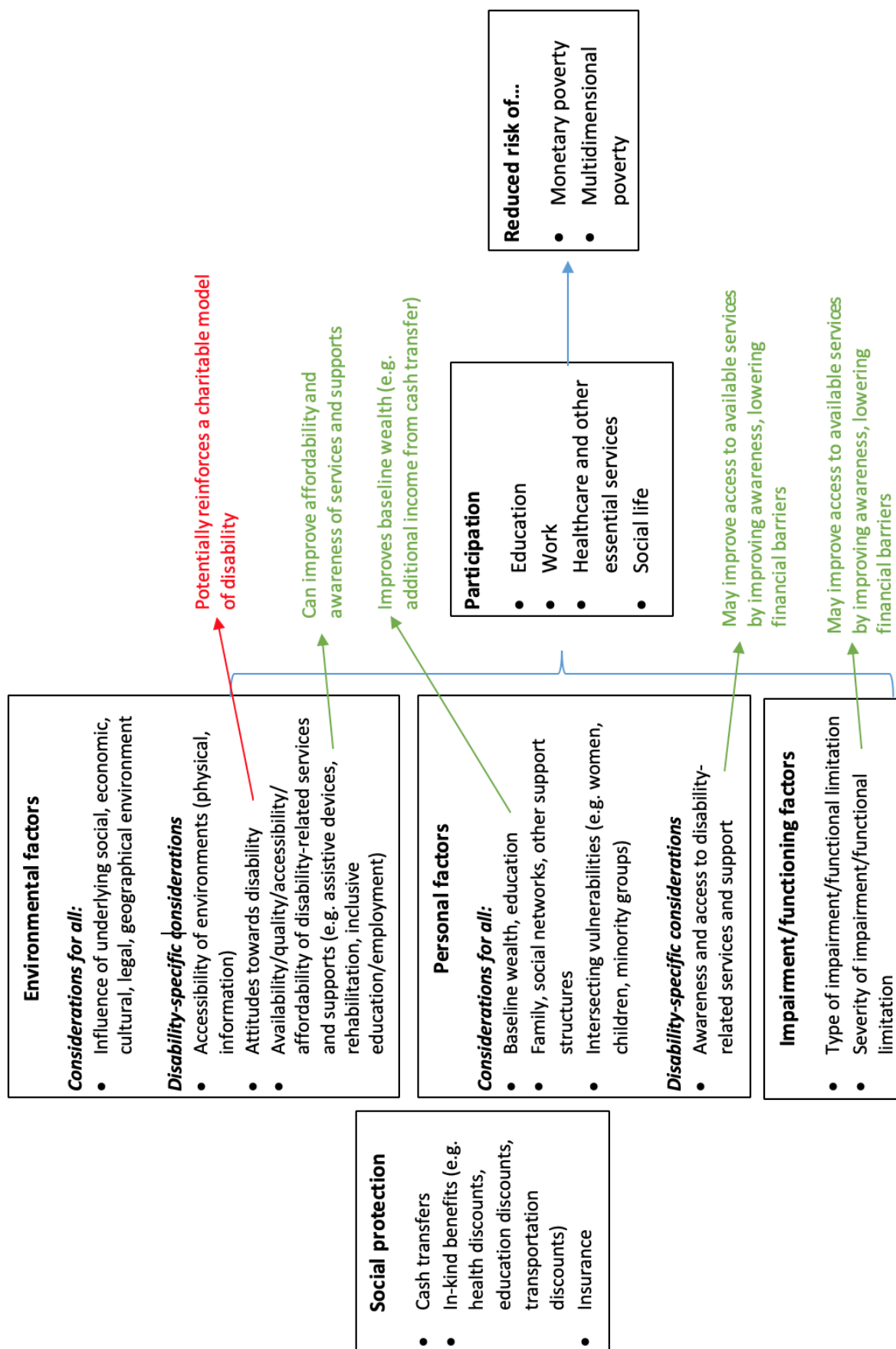


The research contained in this thesis carries several implications for policy, programmes and research on poverty, social protection and disability in LMICs.

### ***Understanding the relationship between disability and poverty through the role of social protection***

The conceptual framework on disability and poverty outlined in Figure 1 of Chapter 3 that is embedded in the ICF and theories of poverty can help explain why this research found people with disabilities faced an increased risk of economic and multidimensional poverty compared to people without disabilities, and why poverty risk differed amongst people with disabilities. This research also underscored the importance of different impairment, environmental and personal factors that can drive the relationship between disability and poverty, many of which are not adequately being addressed through the social protection systems studied in this thesis.

Overall, the inadequacy of social protection to protect some recipients with disabilities from poverty may highlight how social protection design and implementation fails to account for the diverse drivers of participation restrictions that lead to poverty amongst people with disabilities (Figure 1). In Vietnam and Nepal case studies, available social protection programmes viewed poverty in multidimensional terms, focusing on participation restrictions across a diverse range of areas such as work, education and social life. However, the benefit packages viewed the predominant barrier to participation as due to the individual's lack of financial resources (e.g. scholarships to cover school fees, health discounts/insurance to decrease out-of-pocket spending, transportation discounts to reduce costs of travel). Lack of financial resources was certainly a key barrier to participation amongst people with disabilities, particularly as seen in the high additional costs of disability. However, the amount provided by different social protection programme was inadequate to cover all the diverse additional costs. Additionally, as seen in Figure 1, there are likely many other environmental, personal and impairment-related factors that drive participation restrictions that lead to economic and multidimensional poverty, which were not being addressed in social protection packages.



In particular, environmental factors were not sufficiently addressed as a cause of participation restrictions leading to poverty amongst people with disabilities in the social protection programmes evaluated. Their omission may explain why social protection failed to adequately protect many people with disabilities from poverty. For example, major causes of participation restrictions leading to poverty amongst people with disabilities are the inaccessibility of environments (e.g. infrastructure, information) and the lack of access to disability-related services and supports. However, the design of benefits indicate a failure to account for these environmental factors. For instance, insurance or cash transfers may improve a person with disabilities' ability to pay for rehabilitation, assistive devices or other healthcare needed to improve functioning and support social participation; however, people may still not access these services if they are not available in their area or are of low quality. Similarly, transportation discounts address an individual's ability to pay for public transportation, but will not improve the individual's ability to travel if available transport options are not disability-accessible or operating in their area.

Another important environmental factor driving participation restrictions leading to poverty are societal attitudes on disability. From this research, there is little evidence that the social protection systems studied were able to reduce stigma on disability, and may even have exacerbated it. For example, a multi-country study in Latin America included in the systematic review (*Paper 2*) found receipt of social assistance increased perceived stigma amongst people with bipolar disorder [15]. The construction of some eligibility criteria may also reinforce a charitable model of disability, such as defining disability in terms of inability to work [16]. Failure to change underlying social attitudes on disability may in turn have impeded the ability of social protection to protect recipients with disabilities from poverty.

In addition to environmental factors, this research also highlighted important personal factors that affect participation restrictions leading to poverty. Notably, individual agency in decision-making, particularly over financial decisions (including the use of social protection benefits), is likely an important determinant of participation and poverty, particularly multidimensional poverty. Agency in financial-decision making has been shown to be an important predictor of multidimensional poverty in studies amongst women, with command over resources potentially more

important than actual resource levels [17]. This research found evidence of a lack of agency in financial decision-making amongst people with disabilities, as almost 40% of adult Disability Allowance recipients in both Vietnam and had no input into how the cash transfer was spent. More research is needed to understand if and how individual agency of people with disabilities, particularly in spending decisions, impacts poverty risk.

Finally, for impairment-related factors, this research affirmed differential poverty risk amongst people with disabilities depending on age of onset, severity and impairment type. For example, the systematic review on disability and economic poverty found that studies of older adults were less likely to report a positive association with poverty compared to studies involving working-age adults or children. This difference likely reflects the influence of age of onset: individuals developing disability in later life will not have had to contend with impairment-related factors that increase the risk of participation restrictions during their school and working years, which can allow them to establish a higher baseline wealth and other safeguards before the onset of disability. Additionally, people with disabilities differed in their risk of poverty based on their type of impairment/functional limitation and its severity. For example, amongst people with disabilities in the Nepal and Vietnam case studies, people with more severe functional limitations and impairments affecting self-care and cognition were more likely to be multidimensionally poor. Similarly, studies on intellectual impairment (in children, working-age adults) and mental health disorders were more likely to find an association between disability and economic poverty in the systematic review. This finding demonstrates how poverty risk is not universal amongst people with disabilities, and that age of onset, impairment type and severity level can create higher barriers to participation, particularly in unaccommodating environments.

The failure of social protection to adequately protect many people with (and without) disabilities from poverty reinforces the importance of the social exclusion and capability approaches for conceptualising poverty amongst people with disabilities, rather than the monetary approach alone. While financial resources are clearly important, people with disabilities faced persistent barriers converting these resources into desired functionings (e.g. being employed, going to school) even if

they were not income poor (*Paper 3*). The role of environmental factors, such as inaccessible environments and stigma, in particular may explain why people with disabilities face an increased risk compared to people without disabilities. Further attention is needed to understand and address the diverse environmental factors, as well as personal and impairment-related factors, that are likely to drive the relationship between disability and poverty.

### ***Measuring poverty amongst people with disabilities***

Social protection aims to target both monetary poverty (e.g. ensuring a minimum income) and multidimensional forms of poverty (e.g. access to services, social inclusion). It is therefore important to combine monetary and multidimensional approaches in determining the need for social protection, as together they provide a more holistic and nuanced understanding of the experience of poverty. Assessments of multidimensional poverty in Vietnam and Nepal reflected that monetary approaches – which are most commonly used for determinations of poverty – are often insufficient as proxies for all forms of deprivation. Notably, many respondents in both settings who were not monetary poor were still multidimensionally poor. Multidimensional poverty assessments also provided important information for informing policy and programmatic responses, as they demonstrated high levels of deprivation and large disparities compared to people without disabilities in the areas of social inclusion and work/old age security.

Additionally, this research highlights the importance of including disability-related extra costs in assessments of poverty. Incorporating extra disability-related costs substantially increased the proportion of people with disabilities living in monetary poverty, which has been mirrored in other studies [18-20]. Accounting for disability-related extra costs is therefore critical when making determinations of poverty, including for social protection eligibility in means-tested programmes.

Finally, it is important to better understand the drivers of poverty amongst people with disabilities. This research outlines a framework of how different impairment, personal and environmental factors may affect an individual's risk of poverty. As this research was cross-sectional in nature, more longitudinal research is needed to establish the effect of proposed drivers. Still, there is good evidence, based on the

inadequacy of social protection to protect many people with disabilities from poverty, that environmental drivers are critical to understanding poverty risk amongst people with disabilities. Further research is needed to explore the role of environmental factors, and their interaction with personal and impairment-related factors, in determining poverty risk amongst people with disabilities.

### ***Improving access of people with disabilities to social protection***

Evidence from Vietnam and Nepal found people with disabilities were more likely to access social assistance compared to people without disabilities (*Chapter 7, Papers 4 & 5*), which is in line with higher levels of need due to the heightened risk of monetary and multidimensional poverty amongst people with disabilities (*Chapter 6, Paper 3*). Still, evidence from the case studies and from the systematic review indicate that many people with disabilities are not accessing social protection benefits that they are eligible for and that large unmet needs remain. Findings from this research also demonstrate potential points of exclusion, as well as strategies for promoting greater access.

First, disability assessment procedures have been widely noted as a common challenge to accessing disability-targeted schemes in many contexts [21-24], which was reinforced in both the systematic review and the case studies. Unlike age or gender, disability is often not a readily identifiable characteristic, leading to technical and ideological challenges in determining eligibility for disability-targeted schemes [21]. In designing criteria for assessing disability, findings from this research support the view amongst many experts that functioning-based approaches are generally preferred to medical approaches (i.e. presence or absence of certain impairments), as they are more in line with the UNCRPD, better capture the impact of disability and require fewer resources to implement [22, 24-26]. For example, key informants in Vietnam noted that changing disability assessment procedures from medical- to functioning-based protocols reduced the need for medical professionals, which in turn allowed the process to be devolved to lower level administrative units. This change was credited with improving geographic and financial accessibility for applicants.

However, this research highlighted that assessors need rigorous training and clear guidelines for functioning-based protocols to be effective. For example, lack of training and guidelines on how to implement the disability assessment criteria led in practice to a reversion from functioning-based protocols to medical documentation of impairments for a large portion of applicants in Nepal. Lack of training was also linked to inconsistencies in decision-making in both settings, which carries implications for equity and may lead to distrust in the process. Additionally, this research also highlights that more evidence is required to provide guidance for implementing functioning-based assessments for certain groups, such as young children or people with psychosocial impairments, which has been noted as a global challenge [27].

Second, application points for all programmes need to be accessible for all people with disabilities. For example, basing applications in urban centres disadvantages people with mobility limitations and people living in remote areas. Respondents in Nepal in particular noted high costs associated with traveling to district capitals to complete applications, which dissuaded some people from applying. In contrast, applications for other social assistance programmes in Nepal and all programmes in Vietnam were conducted at more devolved administrative levels, which greatly improved the ease of the application process for individuals. The mobile outreach camps used in Nepal also present an innovative strategy for improving access to social assistance for people outside of urban centres, which may be applicable to other LMICs with highly centralised concentration of administrative resources.

Third, people with disabilities were not always aware of all the entitlements they were eligible for, or how to apply for them. Generally, awareness of cash transfers was high, as well as health insurance in Vietnam, but other non-cash benefits (e.g. many of the disability-targeted entitlements) were not well known. DPOs in both settings had increasingly become involved in raising awareness amongst their members of available programmes, and in helping them navigate application procedures, which was beneficial for many. However, additional efforts are needed to increase awareness of non-disability targeted programmes and in areas without a strong DPO presence.

Fourth, the perceived quality of some benefits deterred people with disabilities from applying, indicating a need for improved benefit packages that are more relevant to the needs of people with disabilities. Additionally, stronger enforcement mechanisms in Nepal amongst linked service providers are essential for ensuring people with disabilities are able apply their entitlements at point of use.

Finally, people with disabilities were excluded from some non-disability targeted schemes due to the lack of broader social inclusion. Notably, few people with disabilities in either setting accessed social insurance, likely due to the exclusion of people with disabilities from formal sector or steady, well-paid employment. As such, there is a need for social insurance strategies to cover people with disabilities who are not formally employed or who work irregularly, as well as implement complementary interventions to improve employment opportunities for people with disabilities.

### ***Designing and implementing social protection benefit packages to meet the needs of people with disabilities***

The content of social protection benefit packages should be aligned to best meet the needs of people disabilities and address the specific drivers of poverty and vulnerability that they face [6]. However, this research found that social protection did not adequately protect many beneficiaries from monetary and multidimensional poverty (*Chapter 6, Paper 3; Chapter 8*). Improvements in the design and delivery of benefit packages may increase the effectiveness of social protection amongst people with disabilities.

Given high levels of monetary poverty and disability-related extra costs (*Chapter 4, Paper 1; Chapter 6, Paper 3*), it is clear that cash transfers are needed to guarantee basic income security amongst people with disabilities. Cash transfers, as well as in-kind transfers, subsidies and forms of insurance can also offset out-of-pocket spending on disability-related extra costs. However, the value of cash transfers in Nepal and Vietnam were found to be inadequate to cover both disability-related extra costs and the income shortfalls disabled households faced in reaching the poverty line. Additionally, linked benefits (e.g. health insurance/health discounts, transportation subsidies) did not sufficiently target sources of extra costs due to



problems in design (e.g. lack of coverage of rehabilitation and assistive devices in health insurance) or implementation (e.g. poor compliance amongst service providers in honouring entitlements), likely leading to continued out-of-pocket spending.

Additionally, assessments of multidimensional poverty amongst people with disabilities in Vietnam and Nepal indicated barriers to accessing services (e.g. healthcare, water, sanitation) and developing stronger livelihoods, as well as widespread social exclusion. However, both the systematic review (*Chapter 5, Paper 2*) and the case studies in Vietnam and Nepal (*Chapter 8*) reported that social protection does not lead to sufficient improvements areas. This finding indicates a need for more transformational approaches to social protection, including integrated poverty reduction programmes.

In theory, disability-targeted social protection in Vietnam and Nepal could be described as integrated poverty reduction programmes, as they combine cash transfers with a range of other entitlements (e.g. educational scholarships, vocational training or health insurance/discounts), which have the goal of addressing multiple drivers of poverty, vulnerability and exclusion. However, the design and implementation of some of these benefits likely limits their effectiveness in providing transformational social protection. For example, vocational training programmes were reported to not provide recipients with marketable skills for competitive employment in their local economy, limiting their utility for developing stronger livelihoods. Similarly, health insurance and health discounts did not sufficiently cover rehabilitation, assistive devices and other specialist services, which likely limited access to these needed services for many social protection recipients. Correcting these problems in the design and delivery of linked benefits may increase their effectiveness at contributing to a more transformational approach to social protection.

Finally, the systematic review and the case studies in Vietnam and Nepal also demonstrated that the need for social protection differs amongst people with disabilities. For example, people with functional limitations affecting self-care and cognition were particularly at risk of multidimensional poverty in Vietnam and Nepal. Further, the systematic review, and findings from Vietnam, found working-age adults

were at heightened risk of monetary poverty. Additionally, some individuals were only multidimensionally poor but not monetary poor (or vice versa, particularly in Vietnam). These findings may carry implications for the design of benefit packages so they can respond to the diversity of individual needs, which is a key recommendation from the UN Special Rapporteur report and a joint statement on disability-inclusive social protection systems signed by the ILO, various UN agencies and international disability organisations [6, 28]. For example, programmes for working-age adults may require a stronger emphasis on vocational training and employment supports (e.g. workplace accommodations), while people with functional limitations in self-care and cognition may require personal assistance and other supports to promote autonomy and independent living. Similarly, some people with disabilities may require interventions to improve social participation (e.g. access to assistive devices, accommodations), but not necessarily regular financial support. Further, some individuals may experience overlapping vulnerabilities (e.g. older adult with a disability, single woman with a disability) and thus benefit from interventions designed to address group-specific drivers of poverty and exclusion.

Social protection systems should design and deliver programmes so that they are relevant to people with disabilities across the lifecycle and account for the heterogeneity of people with disabilities. In Vietnam and Nepal, there is some consideration of differing needs across the lifecycle in the design of linked benefits (e.g. provision for education, employment supports); however, the availability and quality of these programmes is often poor, limiting their utility. Vietnam also provides some adaptations in benefit levels depending on certain characteristics of the recipient: for example, higher Disability Allowance amounts are given to children and older adults with disabilities, and additional caregiver allowances are available for people with high support needs. Still, in both settings, individuals are for the most part restricted to only receiving one type of social assistance and set benefit levels, which does not account for overlapping vulnerabilities (e.g. being a single woman with a disability, older adult with disability in Nepal).

Overall, benefit packages should be of sufficient value to meaningfully cover both basic needs and disability-related costs. Benefits should also be designed and delivered with consideration of the different needs amongst people with disabilities

and across the life course. Further, additional interventions may be needed to directly target social exclusion and marginalisation of disability.

### ***Broader disability-inclusive planning***

It is important to note that many forms of social protection (e.g. cash or in-kind transfers, many types of insurance) primarily address financial barriers that hamper an individual's ability to meet their basic needs, develop stronger livelihoods, participate in society and ultimately escape poverty. Proponents of transformational approaches to social protection emphasise the importance of other factors, such as structural inequalities, discrimination and marginalisation, as strong drivers of vulnerability and poverty – particularly chronic poverty [29, 30]. The presence of non-financial barriers to improving well-being were highlighted by the large proportion of people with disabilities in the case studies in Vietnam and Nepal who were multidimensionally poor – even if not monetary poor. In particular, deprivations in indicators of social inclusion (voting, decision-making) were persistent amongst people with disabilities.

Consequently, there is a need to address legal, social, attitudinal and structural barriers to well-being and inclusion, alongside financial barriers. These barriers may include discrimination and negative attitudes on disability, inaccessible built environments, lack of information in alternative formats and low availability of needed items and services. Addressing these drivers of poverty and exclusion will require complementary interventions to promote the inclusion of people with disabilities across sectors of society. For example, many essential services (e.g. schools, health centres, public transport) require adaptations so that their facilities are physically accessible to people with mobility limitations. These services also must develop strategies for communicating information in formats understood by people with different impairment types (e.g. Braille, sign language). Additionally, there is a need to increase the availability and awareness of services and items that promote the inclusion, independence and overall well-being of people with disabilities (e.g. rehabilitation/assistive devices, inclusive education, personal assistance). Further, strategies to tackle attitudinal barriers to inclusion (e.g. sensitisation campaigns to reduce discrimination and violence) as well as legal reforms and advocacy to protect the rights of people with disabilities are needed [29, 30]. Without these parallel

interventions – which should be available across the life cycle – the social protection entitlements received by people with disabilities are unlikely to have maximal impact, particularly in promoting social inclusion and a sustained escape from poverty.

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## **Chapter 10. Strengths, limitations and recommendations for future research**

Each of the research papers in this thesis presents strengths and limitations of their respective methods and designs. This chapter explores the methodological strengths and limitations across components of the thesis. Recommendations for future research are then discussed.

### **10.1 Strengths and limitations**

The research presented in this thesis includes two systematic reviews as well as case studies in Vietnam and Nepal. The latter focused primarily on quantitative data gathered through population-based surveys and nested case-control studies in Cam Le, Vietnam and Tanahun, Nepal. Complementary qualitative research was conducted, and presented in *Chapter 7, Papers 4 & 5*. Overall, this research used robust methods to collect data and generated many important findings to contribute towards the limited evidence base on the need for, access to and adequacy of social protection amongst people with disabilities. Still, the research nonetheless has limitations that should be taken into consideration when interpreting the results of this body of work.

#### ***Use of systematic reviews to identify gaps in the evidence base***

Systematic reviews were conducted at the outset to gather and assess available evidence relating to disability, poverty and social protection across LMICs. This process collated and critically evaluated available evidence to establish what was known on the topic, as well as identified gaps that could be explored in the primary data collection in Vietnam and Nepal.

These reviews used broad search terms and covered a wide range of academic databases to retrieve relevant articles. Both reviews also followed established protocols (e.g. PRISMA) [1], and employed dual review to minimise accidental omission or bias in inclusion/exclusion decisions.

However, both reviews had several limitations. Notably, both were restricted to texts in English and French and did not cover the grey literature, which could have led to

the exclusion of relevant data. For example, reports published by governmental or non-governmental organisations were not included. Similarly, studies from non-English or French-speaking countries may have been underrepresented. In particular, Latin America – where many countries have well-developed and long-standing social protection systems relative to other LMICs – may have been excluded if they were published in Spanish or Portuguese only. However, many journals or databases (e.g. SciELO) are increasingly translating full-texts or at least abstracts into English to improve dissemination of results [2, 3] and these translated texts were used frequently in the review process. A further concern is that studies or outcome measures with non-significant findings are often less likely to be published, which could skew review findings [4].

Additionally, the conclusions generated from the reviews are dependent on the quality of the underlying data in the included studies. For both reviews, but particularly the social protection review, quality of data was an issue. For example, sample sizes in the latter were often small and recruited through convenience sampling. Moreover, many countries were lacking any adequate data from which to draw conclusions. Finally, very few longitudinal studies were retrieved, which carries implications determining causality and tracking trends over time.

### ***Identification of people with disabilities***

The inconsistency of disability measures was a major source of bias in the systematic reviews, which limited comparisons between studies. Further, some measures and methods for identifying people with disabilities in the included studies may have biased or limited the generalisability of the findings. For example, measures that ask about the presence or absence of disability leads to underreporting – particularly amongst older adults and people with less obvious or severe disabilities – as some people do not want to self-identify as disabled due stigma or understand disability as representing certain, usually severe, conditions [5, 6]. Similarly, for the review on social protection, participants were largely recruited through convenience sampling (e.g. through clinics, DPOs or government registries), causing concern that the samples were not representative of the broader population of people with disabilities.

Overall, the main findings from the poverty review are unlikely to be substantially impacted by inconsistencies in disability measurement. The large number of included studies allowed for disaggregation across disability types and measurement approaches, with all finding a consistent relationship between disability and poverty. However, inconsistent disability measures did preclude the use of meta-analysis, which would have been useful to estimate the magnitude of differences in the risk of poverty between people with and without disabilities. For the review on social protection, the small number of included studies and their higher risk of bias does limit the generalisability of findings, and so findings may be skewed towards the experience of people with more severe/visible impairments or who are better connected to government and DPO services. For both topics, additional research that uses consistent, comparable and robust measures of disability is needed in order to more accurately track trends across time and place.

Quantitative data was collected in Tanahun, Nepal and Cam Le, Vietnam using population-based household surveys that identified people with disabilities using the Washington Group questions (Short Set for Cam Le, modified Extended Set for Tanahun). The use of population-based recruitment greatly increases the generalisability of results and reduces potential sources of bias inherent in other strategies of recruitment. Further, the Washington Group questions used to measure disability have been validated in a range of LMIC contexts and are recommended by the United Nations and other bodies for international comparisons of disability, including for monitoring inclusion under the UNCRPD and SDGs [7-9]. The Washington Group questions ask about reported functioning across activities of daily living [10], which is less stigmatising – and more informative – than single binary questions on disability.

Still, it is likely that disability is underestimated for several reasons, given the low reported prevalence of disability in both settings (2.5% in Cam Le and 3.8% in Tanahun). First, the Washington Group question sets, particularly the Short Set, do not encompass all functional limitations. Notably, many aspects of psychosocial functioning are not captured, except for anxiety and depression in the Extended Set [9]. Second, functioning for all household members was reported by the household head in Vietnam, while in Nepal, individuals 16 years or older reported on their own



functioning if they were present in the home at the time of the interview (62% self-reported). Some evidence has found, however, that proxy reporting may lead to the underestimation of disability, particularly for depression and anxiety [11]. Third, the cut-off for disability used encompassed people experiencing “a lot” of difficulty in at least one activity (or experienced daily symptoms of anxiety or depression at a level described as “a lot”). While these cut-offs are in line with Washington Group recommendations [10, 12, 13], they may exclude people with more mild functional limitations. Fourth, household surveys do not capture homeless or transient populations, or people living in institutions [14]. People with disabilities, however, may be overrepresented in these groups. For example, some studies have found that people with disabilities face an increased risk of homelessness [15-17]. Further, in Vietnam, there are many state institutions for people with severe disabilities, particularly veterans [18], while in Nepal, children with disabilities often attend residential schools [19]. It is also important to note that some of these groups, particularly homeless and transient populations, very likely have different experiences of poverty and accessing social protection benefits, which warrants further research.

Additionally, it should be noted that comparisons between Vietnam and Nepal may be affected by the differences in question sets used to identify people with disabilities in each site. However, this difference is unlikely to be significant, as only 14 (7.3%) adults with disabilities in the Nepal case control were uniquely identified by the additional questions included in the Washington Group Extended Set 3 *Short Set Enhanced* (which includes additional questions on upper body functioning and anxiety/depression) and thus would not have been picked up if only the Short Set had been used. Although small numbers prohibits sufficiently powered analyses in this study, further research would be interesting to determine whether people with disabilities identified in the Extended Set but not the Short Set differ in their experiences of poverty.

A final limitation stemming from approaches to identifying people with disabilities concerns the use of Disability Allowance registers for some analyses. People with disabilities were recruited from both the population-based survey and Disability Allowance registers to ensure that sufficient numbers of people were identified who

were receiving the Disability Allowance in order to be able to understand their experience in applying for and using the programme. Still, Disability Allowance recipients (whether recruited from the survey or the registers) tended to be younger and have more severe and visible impairments (e.g. physical, communication) (*Paper 4 & 5*). For this reason, Disability Allowance register recruits were excluded from comparisons of poverty and adequacy of social assistance between people with and without disabilities, so as to not bias results towards the experience of this subset of people with disabilities. Disability Allowance register recruits were used in analyses to compare characteristics of disability cardholders/social assistance recipients amongst people with disabilities. Since these registers were recruited uniformly each nearby cluster, this limited our ability to explore the effects of geography on access to programmes.

### ***Measuring poverty***

The systematic review on disability and economic poverty included studies that employed a wide range of poverty measures. However, not all of these poverty measures were well validated or relevant to their study settings [20]. In light of these concerns, primary data collection in Cam Le and Tanahun used indicators of poverty that are in line with SDG and national monitoring plans [21, 22]. Further, the combination of both monetary and multidimensional poverty measures provides a more holistic understanding of poverty in each setting, compared to unidimensional poverty measurement.

For monetary poverty, expenditures data is generally preferred to income, particularly in settings where barter or production of goods and service for personal consumption are common [23, 24]. Expenditures data, however, are much more time-consuming to collect, and were not budgeted for in the research grant. For Cam Le, almost all work was remunerated in cash (as reported by over 96% of survey respondents) and thus income is likely a good indicator of wealth. For Tanahun, however, income may not capture all forms of material wealth. For example, almost half of survey respondents in Tanahun who were working reported either not being paid (23%), being paid in kind only (11%) or being paid in both cash and kind (11%). Nepal, however, has one of the world's highest rates of migration, and estimates from the 2010/2011 Nepal Living Standards Survey indicate that over 50% of

households receive cash remittances [25]. Tanahun in particular has one of the highest rates of external migration [26]. Consequently, while income is unlikely to capture all forms of material wealth in Tanahun.

A further concern with monetary poverty measures, and the cross-sectional nature of this study, is that fluctuations in poverty are not captured. Volatility in income (and expenditures) can have a profound impact on a household's well-being, coping strategies and vulnerability to chronic poverty [27-29]. In this study, household heads were asked to report on the average monthly income from all sources; however, households may experience significant fluctuations in income due to issues like irregular employment or inconsistent revenue streams. This volatility not only increases the risk of measurement errors [20], but may mask true poverty levels. For example, many people may be cycling in and out of poverty, but may not be counted in poverty figures if data is collected at one point in time or may be counted as poor when this situation is only temporary. Longitudinal research is needed to better assess the relationship between disability and transient, cycling and chronic poverty.

Measures included in the MPI are more static and thus may provide a better indication of an individual's longer-term well-being than the monetary poverty measures. MPIs also explore other aspects of poverty beyond material wealth. The MPI used in Chapters 6 and 8 was developed to reflect the intended goals of social protection, particularly as described in the 2015 annual report of UN Special Rapporteur on the rights of persons with disabilities [30]. This report emphasizes the importance of social protection not just in guaranteeing basic income security, but also in developing stronger livelihoods, improving access to basic services, reducing inequalities and ultimately enhancing independence and social inclusion amongst people with disabilities [30]. The MPI was developed with feedback from Monica Pinilla-Roncancio (one of the co-authors for *Paper 3*), who is an expert on multidimensional poverty measurement, to further improve the validity of the measure. Finally, robustness testing across different MPI structures and poverty cut-offs was undertaken, with all iterations findings people with disabilities had higher levels of multidimensional poverty compared to people without disabilities.

Still, the MPI carries some limitations. Notably, participatory approaches are recommended to directly involve people from a study setting in defining appropriate

and locally-relevant indicators of poverty [31]. Unfortunately, such a piece of work was not funded in the grant that covered this research. As a consequence, the indicators included in the MPI may not have been those most relevant in the lives of people with disabilities in these settings. Additionally, some of the indicators within the MPI may underestimate deprivation. For example, evaluating food security and use of certain assets at the individual-level rather than household-level was not undertaken but would better reflect an individual's well-being. Similarly, including assessments on quality for both the employment and healthcare access indicators would improve their utility in informing policy decisions. Although measures of quality are important for all, their exclusion may particularly underestimate deprivation amongst people with disabilities. For instance, in addition to lower labour force participation, when people with disabilities do work, they are less likely than people without disabilities to have stable, high quality employment [32, 33]. Including measures of precarious work (casual, seasonal or temporary work), salaries and workplace protections (e.g. safe environments, social protection benefits for workers) may provide more nuance to inform policy responses [34]. However, this data can be difficult to accurately collect, and guidelines for setting cut-offs for determining deprivation are lacking.

### ***Measuring extra costs of disability***

Almost no studies in the systematic review on poverty included estimates of extra costs in their poverty comparisons between people with and without disabilities, which likely leads to the underestimation of monetary poverty amongst people with disabilities [35]. Case studies in Nepal and Vietnam therefore adjusted national and international poverty lines by extra costs of disability, using the Standard of Living approach [36]. This approach calculates the magnitude of the direct costs of disability (e.g. for disability-related items such as assistive devices, rehabilitation/specialist healthcare, added transport or personal assistance) by analysing the additional household income needed to raise a disabled household to the same standard of living as an otherwise similar household (e.g. same income, composition) [35]. Incorporating these costs substantially raised the poverty headcount and gap amongst people with disabilities in both settings, providing a more accurate picture of economic well-being amongst disabled households.

Still, the Standard of Living approach does not capture many aspects of economic disadvantage faced by people with disabilities. First, opportunity costs, such as forgone education, unemployment or underemployment of people with disabilities and/or their caregivers, are not included [37]. These costs may be reflected in lower income levels, however, it can be difficult to disentangle their magnitude. Second, the Standard of Living approach does not identify the source of extra costs, which are important for designing interventions to alleviate out-of-pocket spending on these items. Healthcare spending appears to be a large source of extra costs, given that a fifth of disabled households in both settings had spent over a quarter of their monthly income on healthcare expenditures in the last month (*Chapter 6, Paper 3*). In both countries, social protection benefits such as health insurance in Vietnam or subsidies in Nepal do not cover many disability-specific health services and devices, which may explain high out-of-pocket healthcare spending (*Chapter 7, Papers 4 & 5*). Third, the Standard of Living approach only captures what households are actually spending, not the costs for all needed items and services. Particularly in LMICs, many services or items might be essential for people with disabilities to participate in society, but they are either unaffordable, unavailable or inaccessible [35]. The true extra costs of disability needed for full participation are therefore likely to be even higher than the costs estimated. Finally, extra costs estimates do not provide any information about the impact of that spending. Notably, it is not known whether spending on disability-related costs actually translates into improved functioning, participation and well-being. For example, people with disabilities may have high spending on healthcare, but still not access needed services, or receive poor quality care when they do [38]. Similarly, coping strategies used to finance these expenses (e.g. selling off productive assets, taking out loans), while often the only option, may lead to or worsen poverty [38, 39].

### ***Measuring participation in social protection***

Most studies that explored access to social protection in the systematic review on social protection focused on barriers to participation. Only one study provided estimates of coverage or enrolment rates, and no study compared participation between people with and without disabilities. Further, most studies focused only on disability-targeted programmes.

Data collection in Cam Le and Tanahun, however, used population-based surveys to directly measure participation in a wide range of social protection schemes and included comparisons to people without disabilities. Pilot testing of all questionnaires was undertaken before data collection, which helped to ensure terms used to define and describe programmes were recognisable to and understood by survey participants. Data collectors were also instructed on ways to further explain programmes in cases of uncertainty. Still some respondents, particularly proxy respondents, may not have known all of the requested details on programme enrolment, for example, if health insurance was government subsidised or not or if a particular linked benefit had been used; however, this is not likely to be a large source of measurement error.

### ***Assessing impact and adequacy***

Twelve studies included in the systematic review on social protection explored its impact amongst people with disabilities. However, all studies were cross-sectional or qualitative, meaning that it was not possible to observe differences in poverty indicators over time, particularly pre- and post-enrolment. Further, measures of impact were self-reported or relied on long recall periods, which may have led to measurement errors or recall bias.

Likewise, case studies in Vietnam and Nepal used cross-sectional designs, and so faced similar challenges objectively measuring the impact of participation in social protection amongst people with disabilities. Instead, adequacy was assessed by comparing levels of deprivation amongst social assistance recipients with disabilities (e.g. proportion living below national/MPI poverty lines) to non-recipients with disabilities and recipients and non-recipients without disabilities. This approach underscored that social assistance in its current state is insufficient to protect many recipients against poverty and social exclusion. However, without longitudinal data from pre- and post-enrolment, it was not possible to evaluate objectively if social assistance at least somewhat improves these outcomes. It is conceivable that social assistance recipients were even poorer and experienced higher levels of exclusion before enrolment.

Further, most studies in the systematic review, as well as the case studies, focused on social assistance, predominantly Disability Allowances. While other benefits are available, such as forms of social insurance, enrolment numbers were too low in Vietnam and Nepal for sufficiently powered assessments of their adequacy. Similarly, analyses were not adjusted to account for use of benefits linked to cash transfers, due to insufficient variation (i.e. near universal uptake of health insurance, low uptake of other linked benefits) (*Chapter 7, Papers 4 & 5*). Integrated poverty reduction programmes are more likely to alleviate poverty and improve well-being than cash transfers alone [40], and so such an evaluation would be a useful area for further research. Still, qualitative research amongst users of these benefits indicated systemic challenges that are likely to limit their impact.

### ***Identifying predictors of poverty and social protection access***

People with disabilities are a heterogeneous group and so identifying factors that can mitigate or exacerbate poverty and social protection access and impact is important for designing and administering more effective social protection systems. This research revealed several factors linked to poverty and social protection access amongst people with disabilities. For example, people with functional limitations affecting self-care and cognition faced a heightened risk of multidimensional poverty in Vietnam and Nepal. Meanwhile, disability-targeted social assistance coverage was found to be lowest amongst older adults and in people with psychosocial or sensory impairments.

Still, some analyses may have been underpowered to detect all differences amongst participants. Consequently, it is possible that there are other personal and contextual factors that are linked to poverty and social protection access amongst people with disabilities, but the effect size was not large enough to be detected with the available sample sizes. Insufficient sample size also prevented disaggregation of findings on the adequacy of social assistance.

Further, other potential factors of interests (e.g. whether the individual had access to needed disability supports, such as rehabilitation and assistive devices) were not assessed due to the lack of good quality data.

## **10.2 Generalisability of results**

Both systematic reviews collated available evidence from across LMICs. Still, their findings may not be generalizable to all LMICs. Notably, evidence was lacking from many countries and therefore the situation of people with disabilities in these contexts is not represented. For the systematic review on poverty and disability [41], 150 studies were included, which presented data from over 70 countries. However, many of these countries did not have recent data or information about people with different impairment types. Additionally, almost half of the included studies (48%) were from India, China or Brazil<sup>17</sup>. Similarly, for the systematic review on social protection and disability [42], 8 of the 15 (53%) included studies were from South Africa. Therefore, findings may be skewed to reflect conditions in contexts with a more robust evidence-base rather than all LMICs. For both reviews, publication and other sources of bias in included studies (e.g. non-representative sampling) may further limit generalisability of results. Even with these limitations, the systematic review on poverty and disability presents strong evidence that people with disabilities are more likely to be living in economic poverty. The systematic review on social protection and disability, however, highlights the need for more research on this topic.

The case studies in Vietnam and Nepal were not designed to be generalizable to the rest of the country, as data was only collected in one district in each country. These districts (as well as countries) were selected as they were identified as having relatively well-functioning social protection systems that had made strides to be inclusive of people with disabilities. Consequently, results should be interpreted as illustrating strengths and challenges from relatively well-functioning social protection systems, rather than the situation in the rest of the country, or other LMICs.

### **10.3 Recommendations for future research<sup>18</sup>**

The 2015 annual report of the UN Special Rapporteur on the rights of persons with disabilities highlighted the limited availability of research on social protection and disability [30]. While the research presented in this thesis contributes towards expanding the evidence base, many gaps in knowledge still remain. Further research

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<sup>17</sup> However, these countries are home to almost half of all people living in LMICs.

<sup>18</sup> Some research recommendations are included in the original reports submitted to the project funders, which were also written by this PhD candidate.



is thus needed to understand poverty amongst people with disabilities and support the design, delivery and monitoring of evidence-based social protection programmes.

### **On measuring poverty**

1. Undertake participatory research to define appropriate and context-specific indicators of poverty that are relevant to people with disabilities.
2. Investigate extra disability-related costs, including identifying dominant sources, their magnitude, coping strategies for meeting them and their impact. Similarly, evaluate unmet but required disability-related needs, their cost and barriers to meeting them.
3. Conduct longitudinal research amongst people with disabilities to understand changes in poverty over time, including chronic and cyclical poverty.

### **On social protection design and delivery**

4. Identify best practices and tools for assessing disability, including for psychosocial impairments and in young children, which can be used to determine eligibility for disability-targeted schemes. Evaluate the consequences of different approaches in terms of human and material resources required, applicants' experiences and perceived acceptability, and resulting coverage for different subgroups (e.g. by impairment type, age, sex).
5. Explore barriers and facilitators to accessing both mainstream and disability-targeted social protection schemes in other contexts. Further research is needed on inclusion of people with disabilities in schemes not adequately covered in this research, such as conditional cash transfers, means-tested programmes and different forms of insurance.
6. Support monitoring strategies to track access of people with disabilities to both targeted and mainstream schemes. In particular, collection and analysis of disability data in mainstream schemes is lacking.

### **On programme adequacy and impact**

7. Explore the impact of social assistance, health insurance and other social protection provisions amongst people with disabilities through longitudinal impact evaluations and/or randomised controlled trials. Measuring changes

pre- and post-enrolment, and at different time points over the duration of support, can determine more fully if social protection improves living circumstances and well-being for people with disabilities.

8. Assess how policy changes (e.g. introduction of new or adapted benefits, changes in application procedures) affects both access to programmes as well as impact on poverty and social exclusion.

### Across research

9. Disaggregate data on poverty and social protection to account for the heterogeneity of experiences of people with disabilities, due to factors such as sex, age, impairment types and rural/urban residence.
10. Explore the effect of intersecting vulnerabilities (e.g. gender, ethnic minorities) on need for, access to and impact of social protection.
11. Conduct similar research across other LMIC settings to enable comparisons across contexts.

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## **Chapter 11. Conclusion**

The research presented in this PhD thesis sought to contribute to the evidence base on the need for, access to and adequacy of social protection amongst people with disabilities in LMICs. Overall, this research found high levels of monetary and multidimensional poverty amongst people with disabilities, as well as large inequalities compared to people without disabilities. Evidence from Vietnam and Nepal indicated that this increased need for social protection may be matched through higher enrolment in some programmes, particularly social assistance, compared to people without disabilities. However, many people with disabilities are not accessing programmes they are entitled to. Additionally, receipt of social protection – namely social assistance – does not guarantee recipients are protected from different forms of poverty. In particular, social protection programmes in their current state appear inadequate in promoting social inclusion and stronger livelihoods for many recipients with disabilities.

Transformational approaches to social protection are needed to improve its effectiveness amongst people with disabilities. Such approaches may include ensuring cash and non-cash benefits received by people with disabilities are sufficient to cover for both basic needs as well as disability-related extra costs. Moreover, the design and delivery of non-cash benefits need to be strengthened to provide meaningful livelihood development and social inclusion of people with disabilities. Benefit packages should also consider heterogeneity amongst people with disabilities and throughout the life-cycle. Further, complementary, multisectoral strategies are necessary to promote the inclusion of people with disabilities across all sectors of society in order to increase access to social protection and maximising its benefits. Barriers encountered by people with disabilities during the application process, such as complex, costly and poorly understood application processes, also should be tackled to increase enrolment amongst people with disabilities. Finally, people with disabilities should be involved across all stages of social protection design and delivery to ensure systems are adequately reaching people with disabilities and meeting their needs.

## **SECTION E      APPENDICES**

## Appendix 1: Ethics approvals

### *Ethics from Nepal*



Government of Nepal  
**Nepal Health Research Council (NHRC)**  
Estd. 1991



Ref. No.: 149.

04 August 2016

**Ms. Hannah Elizabeth Kuper**  
Principal Investigator  
London School of Hygiene and Tropical Medicine  
London, UK

Ref: **Approval of Research Proposal** entitled **Need for and access to the disability allowance and other forms of social protection among people with disabilities in Nepal: a case study from Tanahaun district**

Dear Ms. Kuper,

It is my pleasure to inform you that the above-mentioned proposal submitted on 15 June 2016 (Reg.no.169/2016 please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 03 August 2016.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol before the expiration date of this approval. Expiration date of this study is December, 2016.


If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the total research amount is **NRs. 34,28,500.00** and accordingly the processing fee amount to **NRs. 1,02,855.00**. It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E section of NHRC.

Thanking you

  
Dr. Khem Bahadur Karki  
Member-Secretary



MINISTRY OF HEALTH  
HANOI SCHOOL OF PUBLIC HEALTH

SOCIALIST REPUBLIC OF VIETNAM  
Independence – Freedom - Happiness

No.: 261/2016/YTCC-HD3  
Subject: Ethical Approval

Ha Noi, April 28, 2016

**DECISION**

**On Ethical approval for research involving human subject participation**

THE CHAIR OF THE ETHICAL REVIEW BOARD FOR BIOMEDICAL RESEARCH  
HANOI SCHOOL OF PUBLIC HEALTH

- Based on Decision No. 116/QĐ-YTCC by the Dean of Hanoi School of Public Health on Establishment of The Institutional Ethical Review Board of Hanoi School of Public Health; 02 February 2015 ;
- Based on decision No. 651/QĐ-YTCC by the Dean of Hanoi School of Public Health on the Issuing Regulation of the Institutional Ethical Review Board of Hanoi School of Public Health; 26 June 2015;
- After reviewing research ethics application No. 016-261/DD-YTCC;

**DECIDED**

Article 1. Grant ethical approval for ethnographic study project:

- Project Title: **Research into Disability - Inclusive Social Protection Systems**
- Investigator: **Assoc Prof. Hoang Van Minh**- Hanoi School of Public Health
- Implementation agency: Centre for Population Health Sciences- Hanoi School of Public Health- 138 Giangvo str., Hanoi, Vietnam
- Sponsor: London School of Hygiene and Tropical Medicine
- Research site: Da Nang city
- Project time: from 02/05/2016 to 30/11/2016
- Pilot and data collection time: from 01/06/2016 to 30/09/2016
- Review type: Expedited review

Article 2. This decision is effective from 02/05/2016 to 30/11/2016

Article 3. Principal Investigator has to send progress report once each year and a final report upon the study completion to the Institutional Ethical Review Board of Hanoi School of Public Health (IRB of HSPH).

Article 4. Principle Investigator should notify (IRB of HSPH) immediately of any adverse effects arising from this study (e.g. unexpected adverse outcomes, unexpected community/subject risk factors or complaints, etc.). Active research projects are subject to random audit by the IRB of HSPH.

**CHAIR OF INSTITUTIONAL ETHICAL REVIEW BOARD**

**SECRETARY**

(Signature and full name)

(Signature and full name)



Ha Van Nhu



Nguyen Thi Minh Thanh



## Ethics from London School of Hygiene & Tropical Medicine

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#### Observational / Interventions Research Ethics Committee

Dr Karl Blanchet

Lecturer

Department of Global Health and Development (GHD)

Public Health and Policy (PHP)

LSHTM

18 February 2016

Dear Karl

**Study Title:** Disability-Inclusive Social Protection Systems

**LSHTM Ethics Ref:** 10497

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Short CV Hannah 2015	14/12/2015	1
Investigator CV	CV Karl Blanchet One Page	14/12/2015	1
Protocol / Proposal	Household Disability Screening Questionnaire_Inclusive SP Project	14/12/2015	1
Protocol / Proposal	Case Control Questionnaire_Inclusive SP Project	14/12/2015	1
Protocol / Proposal	Disability Grant Questionnaire_Inclusive SP Project	14/12/2015	1
Investigator CV	CV NEW_1 page-Morgon Banks	14/12/2015	1
Investigator CV	CV NEW_1 page - Matthew Walsham	14/12/2015	1
Protocol / Proposal	Protocol_Disability-Inclusive Social Protection Project	17/12/2015	v1
Information Sheet	Participant information sheet 2 -Nested case-control	01/01/2016	1
Information Sheet	Participant Information sheet 1 - Household screening	27/01/2016	1
Information Sheet	Participant information sheet 4 - in-depth interviews	27/01/2016	1
Information Sheet	Participant information sheet 3 - social protection participants	28/01/2016	1
Covering Letter	Covering Letter 2	16/02/2016	1
Information Sheet	Participant information sheet 5 - Key Informants	16/02/2016	2

#### After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

Yours sincerely,

Professor John DH Porter  
Chair

[ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk)

<http://www.lshtm.ac.uk/ethics/>

## Appendix 2: Information sheets and consent forms

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### PARTICIPANT INFORMATION SHEET 1

#### BASELINE HOUSEHOLD SCREENING SURVEY

**You and your household are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. I will read information to you about this study. Please ask me if there is anything that is not clear or if you would like more information.**

**What is the purpose of the study?** We are conducting a study to find out how many people with disabilities there are within this district and the types of disabilities.

**Why have I been chosen?** We have randomly selected 60 villages in the district and are inviting all people in these areas to take part in the study. You and your household been chosen because your house is in one of these areas.

**What is involved in the study?** We will ask you to answer some questions about who usually lives in your house and about the socio-economic condition of the household. For each member of your household we will ask you to tell us if he/she experiences difficulties with 6 different activities (e.g. seeing, hearing, walking, understanding, communicating, and self-care). This will take about 15 minutes.

If you/your child(ren) have a disability we would like to invite you/your child(ren) to take part in an interview during which you will be asked further questions about different aspects of your/your child(ren)'s life. This will be explained in a separate participant information sheet, as needed.

**Which groups are organising the survey?** This study is being organised by [ local research partner – VaRG or HUPH] which is a national research organisation. It is supported by the London School of Hygiene and Tropical Medicine, a university based in London. Funding for the study comes from DFAT, which is the Australian Department of Foreign Affairs and Trade.

**Confidentiality** All information which is collected about you/your child(ren) during the course of the research will be kept strictly confidential. This information will not be shared with anyone else.

**What are the benefits?** If you/your child have a disability and the survey teams finds you could benefit from a particular service that is available related to your disability, you will be informed of this and referred to this service. The information in this survey will allow us to estimate how many people have disabilities. This information can be used to plan services, and to lobby organisations to invest more funds in disability.

**What are the risks?** There are no risks of physical or psychological harm associated with this survey. The questions will take up a bit of your time – about 15 minutes per household. You will not receive a financial or other type of reimbursement for taking part in the study.

**Do I have to take part?** No. It is up to you to decide whether or not to take part. If you decide not to take part it will not have an affect on any of the services that you receive. If you/your child(ren) agree to take part you are still free to withdraw at any time and without giving a reason.

*Local Research Lead:*

*For Vietnam: [Named individual and contact details from HUPH]*

*For Nepal: [Named individual and contact details from VaRG]*



## CONSENT FORM 1

### BASELINE HOUSEHOLD SCREENING SURVEY

**Participant:** (First & Last Name) \_\_\_\_\_

Cluster No: \_\_\_\_\_ Household No.: \_\_\_\_\_ Subject No: \_\_\_\_\_

1. The information sheet concerning this study has been read to me and I understand what is required of me/my child if I take part in it
2. I have been given the opportunity to ask questions and a reply was given for all the questions to my satisfaction.
3. I understand that participation is voluntary and that I may withdraw at any time without giving a reason

---

**Consent for Adult to Participate**

\_\_\_\_\_  
Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature/Thumbprint

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Participant information sheet 2**

### **Nested Case/Control study**

**You/your child(ren) are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. I will read information to you about this study. Please ask me if there is anything that is not clear or if you would like more information.**

#### **What is the purpose of the study?**

We are conducting a study to find out about the experiences of people with disabilities and their access to services in your area.

#### **Why have I been chosen?**

**For a case:** You/your child have been selected because of the difficulty with activities that you reported that you experience.

**For a control:** You/your child have been randomly selected as a person living in the study area.

#### **What is involved in the study?**

We have developed a questionnaire to ask about different aspects of your/your child(ren)'s life. We will ask you each question and request that you give us the information. This will include questions about whether or not you use local services regularly, whether you are currently working, and if your child is attending school. The interview will take about 30-45 minutes.

#### **Which groups are organising the survey?**

This study is being organised by [local research partner: VaRG or HUPH] which is a national research organisation. It is supported by the London School of Hygiene and

Tropical Medicine, a university based in London. Funding for the study comes from DFAT, which is the Australian Department of Foreign Affairs and Trade.

**Confidentiality** All information which is collected about you/your child during the course of the research will be kept strictly confidential. This information will not be shared with anyone else.

**What are the benefits?** If you/your child have a disability and the survey teams finds you could benefit from a particular service that is available related to your disability, you will be informed of this and referred to this service. In addition the information collected in this survey can help to plan and improve services that are available for people with disabilities, and to advocate for change where this is needed.

**What are the risks?** There are no risks of physical or psychological harm associated with this survey. The questions will take up a bit of your time – about 30-45minutes. You will not receive a financial or other type of reimbursement for taking part in the study.

**Do I have to take part?** No. It is up to you to decide whether or not to take part. If you decide not to take part it will not have an effect on any of the services that you receive. If you/your child agree to take part you are still free to withdraw at any time and without giving a reason.

**Local Research Lead:**

*For Vietnam: [Named individual and contact details from HUPH]*

*For Nepal: [Named individual and contact details from VaRG]*



## CONSENT FORM 2

### NESTED CASE CONTROL STUDY

**Participant:** (First & Last Name) \_\_\_\_\_

Cluster No: \_\_\_\_\_ Household No.: \_\_\_\_\_ Subject No: \_\_\_\_\_

4. The information sheet concerning this study has been read to me and I understand what is required of me/my child if I take part in it
5. I have been given the opportunity to ask questions and a reply was given for all the questions to my satisfaction.
6. I understand that participation is voluntary and that I may withdraw at any time without giving a reason

#### Consent for Adult to Participate

Name	Date	Signature/Thumbprint
------	------	----------------------

Witness	Date	Signature
---------	------	-----------

#### Consent for Child to Participate.

Relationship to child of person giving consent: \_\_\_\_\_

Name	Date	Signature/Thumbprint
------	------	----------------------

Witness	Date	Signature
---------	------	-----------

## Participant information sheet 3

### Survey of Disability Allowance recipients

**You/your child(ren) are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. I will read information to you about this study. Please ask me if there is anything that is not clear or if you would like more information.**

#### **What is the purpose of the study?**

We are conducting a study to find out how the social protection programme in which you are enrolled considers the needs of disabled people.

#### **Why have I been chosen?**

You/your child have been selected because you receive a disability grant from the Government social assistance programme.

**What is involved in the study?** We will ask you to answer some questions about who usually lives in your house and about the socio-economic condition of the household. For each member of your household we will ask you to tell us if he/she experiences difficulties with 6 different activities (e.g. seeing, hearing, walking, understanding, communicating, and self-care).

For each household member we will ask: whether or not they are a disability grant; if they have used government services such as health, education and livelihoods services in the last six month; and, if so, what. We will also ask about satisfaction with the disability grant, for people enrolled in this scheme. The interview will take about 20 minutes.

**Confidentiality** All information which is collected about you/your child during the course of the research will be kept strictly confidential. This information will not be shared with anyone else.



**Which groups are organising the survey?** This study is being organised by [i local research partner: VaRG or HUPH] which is a national research organisation. It is supported by the London School of Hygiene and Tropical Medicine, a university based in London. Funding for the study comes from DFAT, which is the Australian Department of Foreign Affairs and Trade

**What are the benefits?** If you/your child have a disability and the survey teams finds you could benefit from a particular service that is available related to your disability, you will be informed of this and referred to this service. In addition the information collected in this survey will help to assess whether the disability grant meets the needs of people with disabilities, and if not how it can be improved.

**What are the risks?** There are no risks of physical or psychological harm associated with this survey. The questions will take up a bit of your time – about 20 minutes. You will not receive a financial or other type of reimbursement for taking part in the study.

**Do I have to take part?** No. It is up to you to decide whether or not to take part. If you decide not to take part it will not have an effect on any of the services that you receive, including with respect to the disability grant. If you/your child agree to take part you are still free to withdraw at any time and without giving a reason.

***Local Research Lead:***

*For Vietnam: [Named individual and contact details from HUPH]*

*For Nepal: [Named individual and contact details from VaRG]*

## CONSENT FORM 3

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### DISABILITY ALLOWANCE SURVEY

**Participant:** (First & Last Name) \_\_\_\_\_

Cluster No: \_\_\_\_\_ Household No.: \_\_\_\_\_ Subject No: \_\_\_\_\_

1. The information sheet concerning this study has been read to me and I understand what is required of me/my child if I take part in it
2. I have been given the opportunity to ask questions and a reply was given for all the questions to my satisfaction.
3. I understand that participation is voluntary and that I may withdraw at any time without giving a reason

---

#### Consent for Adult to Participate

_____	_____	_____
Name	Date	Signature/Thumbprint

_____	_____	_____
Witness	Date	Signature

#### Consent for Child to Participate.

Relationship to child of person giving  
consent: \_\_\_\_\_

_____	_____	_____
Name	Date	Signature/Thumbprint

_____	_____	_____
Witness	Date	Signature

## Appendix 3: Household questionnaire<sup>19</sup>

### SOCIAL PROTECTION & DISABILITY STUDY Household Disability Screening Questionnaire, 2016

<b>A: Cover Sheet</b>			
1.	Date (Day/Month/Year):		
2.	Cluster name		
3.	Cluster No.		
4.	House No.		
5.	Interviewer No.		
6.	Availability/consent of household for survey	Available for survey .....1 Not available .....2 Refused .....3	
7.	Location	Urban.....1 Rural.....2	
8.	Total number of eligible household members aged 5+ years	Number: _____	

<sup>19</sup> This is the questionnaire used in Nepal. The questionnaire used in Vietnam is similar, with some context-specific differences.

B. Household roster						
9. How many people, including yourself, normally live (at least 3 months of year) in this household and share a kitchen?		2. Gender		3 What is age?	4. Is he/she currently attending/ever attended school?	5. Current grade or highest grade completed
ID No.	Person's Name <i>List fist name and family name</i>	Male	Female	<i>Enter age in completed years</i>	1= Yes, still studying 2= Yes, but no longer studying 3=No, never	1= Some primary school (not complete) 2= Primary school 3= Some secondary school 4= SLC 5= College/university 6= Don't know
1		1	2			
2		1	2			
3		1	2			
4		1	2			
5		1	2			
6		1	2			
7		1	2			
8		1	2			
9		1	2			
10		1	2			
11		1	2			
12		1	2			
13		1	2			
14		1	2			

10) What is the ethnicity/caste of the household?

1= Brahmin

2= Chhetri

3= Dalit

4= Janajati

5= Newar

6= Muslim

7= Other (specify)

## C. Screening questions

*I am now going to ask you some questions about certain everyday activities, and whether each person has any difficulties in doing them. Please tell me if you do not understand question, and I will repeat it.*

CHILDREN 5-15 YEARS (CAREGIVER REPORT) <sup>20</sup>		
<b>CF1.</b> I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE.  DOES (name) WEAR GLASSES OR CONTACT LENSES?	Yes.....1 No.....2	2⇒CF3
<b>CF2.</b> WHEN WEARING HIS/HER GLASSES OR CONTACT LENSES, DOES (name) HAVE DIFFICULTY SEEING?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇒CF4 2⇒CF4 3⇒CF4 4⇒CF4
<b>CF3.</b> DOES (name) HAVE DIFFICULTY SEEING?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF4.</b> DOES (name) USE A HEARING AID?	Yes.....1 No.....2	2⇒CF6
<b>CF5.</b> WHEN USING HIS/HER HEARING AID, DOES (name) HAVE DIFFICULTY HEARING?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇒CF7 2⇒CF7 3⇒CF7 4⇒CF7
<b>CF6.</b> DOES (name) HAVE DIFFICULTY HEARING?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF7.</b> COMPARED TO OTHER CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF8.</b> COMPARED TO OTHER CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF9.</b> COMPARED WITH CHILDREN OF THE SAME AGE AND USING [HIS/HER] USUAL LANGUAGE, DOES (NAME) HAVE DIFFICULTY UNDERSTANDING OTHER PEOPLE?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	

<sup>20</sup> UNICEF-Washington Group Child Functioning Question Sets (Washington Group and UNICEF. Child Functioning Question Sets. 2018; Available from: <http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/>); N.B. In Vietnam the Washington Group Short Set was used for all participants.

WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?		
<b>CF10.</b> COMPARED WITH CHILDREN OF THE SAME AGE AND USING [HIS/HER] USUAL LANGUAGE, DOES (NAME) HAVE DIFFICULTY BEING UNDERSTOOD BY OTHER PEOPLE?  WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF11.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES <i>(name)</i> HAVE DIFFICULTY LEARNING TO DO NEW THINGS?  WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF12.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES <i>(name)</i> HAVE DIFFICULTY REMEMBERING THINGS THAT THEY HAVE LEARNED?  WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>CF13.</b> COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES [HE /SHE] WORRY OR FEEL SAD?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	The same or less.....1 More.....2 A lot more.....3	
<b>[FOR CHILDREN MEETING STUDY DEFINITION OF DISABILITY]</b> DO YOU CONSIDER [NAME1] TO HAVE A DISABILITY?	Yes.....1 No.....2	

<b>ADULT (16+ YEARS) – INDIVIDUAL SELF-REPORTS IF PRESENT<sup>21</sup></b>		
<b>AF0. [FOR INTERVIEWER] IS [NAME] RESPONDING FOR HIM/HERSELF?</b>	Yes.....1 No.....2	
<b>AF1.</b> DO YOU WEAR GLASSES OR CONTACT LENSES?	Yes.....1 No.....2	2⇒AF3
<b>AF2.</b> DO YOU HAVE DIFFICULTY SEEING, EVEN WHEN WEARING YOUR GLASSES/CONTACT LENSES?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇒AF4 2⇒AF4 3⇒AF4 4⇒AF4
<b>AF3.</b> DO YOU HAVE DIFFICULTY SEEING?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF4.</b> DO YOU USE A HEARING AID?	Yes.....1 No.....2	2⇒AF6
<b>AF5.</b> DO YOU HAVE DIFFICULTY HEARING, EVEN WHEN USING YOUR HEARING AID(S)?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇒AF7 2⇒AF7 3⇒AF7 4⇒AF7

<sup>21</sup> Washington Group Extended Set (Washington Group on Disability Statistics. Washington Group - Extended Question Set on Functioning (WG ES-F). 2011; Available from: [http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/WG\\_Extended\\_Question\\_Set\\_on\\_Functioning.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/WG_Extended_Question_Set_on_Functioning.pdf)). N.B. Washington Group Short Set was used in Vietnam

<b>AF6. DO YOU HAVE DIFFICULTY HEARING?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF7. DO YOU USE ANY EQUIPMENT OR RECEIVE HELP FOR GETTING AROUND?</b>	Yes.....1 No.....2	2⇒AF9
<b>AF8. DO YOU HAVE DIFFICULTY WALKING OR CLIMBING STEPS, EVEN WHEN USING YOUR EQUIPMENT OR WITH HELP?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇒AF10 2⇒AF10 3⇒AF10 4⇒AF10
<b>AF9. DO YOU HAVE DIFFICULTY WALKING OR CLIMBING STEPS?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF10. USING YOUR USUAL LANGUAGE, DO YOU HAVE DIFFICULTY COMMUNICATING, FOR EXAMPLE UNDERSTANDING OR BEING UNDERSTOOD?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF11. DO YOU HAVE DIFFICULTY WITH SELF-CARE, SUCH AS WASHING ALL OVER OR DRESSING?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF12. DO YOU HAVE DIFFICULTY RAISING A 2 LITRE BOTTLE OF WATER OR SODA FROM WAIST TO EYE LEVEL?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF13. DO YOU HAVE DIFFICULTY USING YOUR HANDS AND FINGERS, SUCH AS PICKING UP SMALL OBJECTS, FOR EXAMPLE A BUTTON OR PENCIL, OR OPENING OR CLOSING CONTAINERS OR BOTTLES?</b>  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
<b>AF14. HOW OFTEN DO YOU FEEL WORRIED, NERVOUS OR ANXIOUS?</b>  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	Daily.....1 Weekly.....2 Monthly.....3 A few times a year.....4 Never.....5	5⇒AF16
<b>AF15. THINKING ABOUT THE LAST TIME YOU FELT WORRIED, NERVOUS OR ANXIOUS, HOW WOULD YOU DESCRIBE THE LEVEL OF THESE FEELINGS?</b>  WOULD YOU SAY:	A little.....1 A lot.....2 Somewhere between a little and a lot.....3	
<b>AF16. HOW OFTEN DO YOU FEEL DEPRESSED?</b>  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	Daily.....1 Weekly.....2 Monthly.....3 A few times a year.....4 Never.....5	5⇒AF18

<b>AF17.</b> THINKING ABOUT THE LAST TIME YOU FELT DEPRESSED, HOW DEPRESSED DID YOU FEEL?  WOULD YOU SAY:	A little.....1 A lot.....2 Somewhere between a little and a lot.....3	
<b>AF18.</b> [FOR CHILDREN MEETING STUDY DEFINITION OF DISABILITY] DO YOU CONSIDER [NAME1] TO HAVE A DISABILITY?	Yes.....1 No.....2	

## Section D. Socioeconomic Status<sup>22</sup>

Q. #	Question	Codes	Go to Q
1	What is the major construction material of the external walls? (Observe, don't ask)	<u>Natural walls</u> No walls.....1 Cane/palm/trunks.....2 Mud/sand .....3 <u>Rudimentary walls</u> Bamboo with mud .....4 Stone with mud.....5 Plywood .....6 Cardboard .....7 Reused wood .....8 <u>Finished walls</u> Cement.....9 Stone with lime/cement .....10 Brick .....11 Cement blocks .....12 Wood planks/shingles.....13 Other, specify.....14	
2	What is the major material of the roof? (Observe, don't ask)	<u>Natural roofing</u> No roof.....1 Thatch/palm leaf.....2 <u>Rudimentary roofing</u> Rustic mat .....3 Palm/bamboo .....4 Wood planks .....5 Cardboard .....6 <u>Finished roofing</u> Galvanized sheet.....7 Wood .....8 Calamine/cement fiber .....9 Ceramic tiles/stone.....10 Cement.....11 Roofing shingles .....12 Other, specify.....13	

<sup>22</sup> Some questions adapted from DHS Surveys (e.g. Demographic and Health Surveys (Ministry of Health and Population [Nepal], New ERA, and ICF International Inc, *Nepal Demographic and Health Survey 2011*, M.o.H.a. Population, Editor. 2012: Kathmandu, Nepal) and World Bank Living Standard Measures (Grosh, M.E. and J. Muñoz, A manual for planning and implementing the living standards measurement study survey. 1996: The World Bank.)



Q. #	Question	Codes	Go to Q
3	What is the primary material of the floor? [Observe, don't ask]	<u>Natural floor</u> Earth/sand .....1 Dung.....2 <u>Rudimentary floor</u> Wood planks .....3 Palm/bamboo .....4 <u>Finished floor</u> Parquet or polished wood .....5 Vinyl or asphalt strips .....6 Ceramic tiles .....7 Cement.....8 Carpet .....9 Other, specify.....10	
4	Which of the following applies to your housing situation?	Own home .....1 Rent home .....2 Rent free (no ownership rights) .....3 Provided by government (free) .....4 Provided by employer.....5 Other (specify) .....6	
5	How many rooms are there in your household used for sleeping?	Number of rooms: _____	
6	What type of toilet is used in your household?	Flush or pour flush toilet.....1 Vented improved pit latrine .....2 Pit latrine with slab .....3 Pit latrine without slab/open pit .....4 Composting toilet .....5 Bucket toilet.....6 No facility/bush/field .....7 Other (specify) .....8	
7	Do you share this toilet facility with other households?	Yes.....1 No.....2	
8	What is the main source of drinking water used by your household?	1=Piped water .....1 2=Public tap/standpipe.....2 3=Tube well or borehole.....3 4=Protected well.....4 5=Unprotected well .....5 6=Protected spring .....6 7=Unprotected spring.....7 8=Rainwater.....8 9=Tanker truck .....9 10= Surface water (river/dam/lake/ pond/ stream/canal/irrigation channel) .....10 11=Stone tap/dhara.....11 12=Bottled water .....12 13=Other (specify) .....13	
9	Where is this water source located?	In own dwelling .....1 In own yard/plot .....2 Elsewhere.....3	→11 →11

Q. #	Question	Codes		Go to Q
10	How does it take to go to the water source and back?	Less than 30 minutes .....1 Between 30 minutes and 2 hours.....2 More than 2 hours .....3		
11	Do you do anything to the water to make it safer to drink (e.g. boil, add bleach/chlorine, use a filter)	Yes.....1 No.....2		
12	What type of fuel does your household mainly use for cooking?	Electricity .....1 Kerosene .....2 Charcoal/coal .....3 Gas .....4 Solar power/renewable energy .....5 Wood/straw/shrubs/plants .....6 Animal dung.....7 No food cooked in household.....8 Other .....9		
13	Is the cooking usually done in the house, in a separate building or outdoors?	In the house .....1 In a separate building .....2 Outdoors .....3 Other .....4		
14	Does any member of your household own the following: (in working order)	Yes	No	
	a Radio/Stereo	1	2	
	b TV/VCR/DVD	1	2	
	c Fridge/Freezer	1	2	
	d Telephone in the house (landline)	1	2	
	e Cell phone	1	2	
	f Cupboard	1	2	
	g Sofa set/arm chair	1	2	
	h Table	1	2	
	i Motor vehicle incl cars	1	2	
	j Motorbike	1	2	
	k Washing machine	1	2	
	l Sewing machine	1	2	
	m Air conditioner	1	2	
	n Bicycle	1	2	
	o Cooker with gas	1	2	
	p Cooker with electric	1	2	
	q Internet access	1	2	
	r Computer	1	2	
15	Does the household have electricity?	1	2	
16	How many of the following does the household own? (Read All)	1 Buffalo/cows/bulls      ## 2 Horses/donkeys/mule      ## 3 Goats/sheep      ## 4 Chickens/ducks      ## 5 Pigs      ## 6 Yaks      ##		

Q. #	Question	Codes		Go to Q
17	Does your household own land for farming or grazing?	Yes.....1 No.....2		2→19
18	If you answered 'yes' in no. 25, what size?	Less than 8 ropani (<1 acre).....1 Between 8-40 ropani (between 1 acre and 5 acres).....2 More than 40 ropani (>5 acres) .....3		
19	In the last 5 years, have any children (including newborns/infants, up to 18 years old) in this household died?	Yes.....1 No.....2		2→21
20	If yes in no.28, what was the cause of death?	Malaria, HIV/AIDS, tuberculosis.....1 Maternal death .....2 Diarrheal disease .....3 Other disease; please name.....4 Accident .....5 Suicide.....6 Violence .....7 Other reason; please name.....8 Don't know.....9		
21	What is your total average monthly income of all the family members (from all sources: salary, allowances, gifts, remittances etc)?	Amount:		
22	How many people in your household contribute to that amount of income?	Number:		
23	Does any member of this household have a bank account/cooperative/or other savings account?	Yes.....1 No.....2		
24	Which category of the following do you think your household income falls into by comparison with those of other families in your area? (Read All)	Rich .....1 Above average .....2 Average .....3 Poor.....4 Very poor .....5		
25	Does anyone in the household currently receive regular instalments of cash (also called cash transfers, social assistance) from the government?	Yes.....1 No.....2		→27
26	Which programme are they enrolled in [tick all that apply]?	Yes	No	
	a Disability Pension	1	2	
	b Old Age Allowance	1	2	
	c Single Women (widow) Allowance	1	2	
	d Pensions/compensation for people who become disabled through work, in times of conflict or while serving in the army	1	2	

Q. #	Question	Codes		Go to Q
	e Child protection grant (for poor Dalit children under 5)	1	2	
	f Other, specify			
27	Does any child in the household receive educational scholarships from the government?	Yes.....1 No.....2		
28	Which household member is a beneficiary of the Disability Pension?	Name: _____		
29	Does anyone in your household have health insurance?	Yes.....1 No.....2		

**Thank you for your time and cooperation in answering my questions.**

## Appendix 4: Case-control questionnaire<sup>23</sup>

### SOCIAL PROTECTION & DISABILITY STUDY

### Case Control Questionnaire, 2016

Cover Sheet			
1.	Cluster name (VDC/ward number)		
2.	Cluster No.		
3.	House No.		
4.	Subject ID No.		
5.	Subject Name:		
6.	Interviewer No.		
7.	Date (Day/Month/Year):		
8.	Is study subject a case or control?	Case (Person with a disability) 1 Control ..... 2	
9.	What is the study subject's age (years)?		
10.	What is the study subject's gender (observe)	Male ..... 1 Female ..... 2	
11.	Is the study subject the head of the household?	Yes ..... 1 No ..... 2	
12.	Is there another case in this household who has already been interviewed?	Yes ..... 1 No ..... 2	<b>2→1 4</b>
13.	If yes, what is that person's ID no?	ID No. _____	
14.	Person interviewed:	Direct interview with case/control ... 1 Interview with proxy only ..... 2 ID of proxy respondent <input type="text"/> <input type="text"/> Interview with proxy and case/control together ..... 3 ID of proxy respondent <input type="text"/> <input type="text"/>	

<sup>23</sup> This is the questionnaire used in Nepal. The questionnaire used in Vietnam is similar, with some context-specific differences. Differences in question types have been highlighted.

SECTION 1: CASES ONLY			
15.	Do you have a disability card?	Yes ..... 1 No..... 2	<b>2→17</b>
16.	NEPAL only What color is your disability card?	Red..... 1 Blue ..... 2 Yellow..... 3 White ..... 4 Don't know ..... 88	<b>All →18</b>
16a.	VIETNAM only: What is your form of disability listed on your card?	Physical disability..... 1 Hearing, speaking disability ..... 2 Vision disability ..... 3 Mental disability ..... 4 Other disability ..... 5	
16b.	VIETNAM only: What is your level of disability listed on your disability card	Extremely disabled ..... 1 Seriously disabled..... 2 Light disabled ..... 3 Don't know..... 88	
17.	(Nepal only) If you do not have a disability card, is there any reason?	I've never heard of this programme ..... 1 Applied, but denied..... 2 I don't think I'm eligible ..... 3 Don't know where to go ..... 4 Application office too far/no transportation..... 5 Application process too complicated ..... 6 Other ..... 7	
18.	(Nepal only) If you have a card, do you ever receive transportation discounts when you use buses or other services?	Yes ..... 1 No..... 2	
19.	(Nepal only) If you have a card, do you ever receive discounted medicine at Government facilities?	Yes..... 1 No..... 2	

## Section 2: Marital Status, Literacy and Education<sup>24</sup>

Now I would like to ask you a few questions about your living status and education

Note to interviewer: If answered by proxy replace "are you" with "is [name]"

Q. #	Question	Codes	Go to Q
<b>For participants 15+ years</b>			
20.	What is your marital status?	Married or living together ..... 1 Divorced/separated ..... 2 Widowed ..... 3 Never married/living together ..... 4	
21.	How many, if any, children have you given birth to/fathered?		<b>0→23</b>
	Of the children you have given birth to/fathered, have any died (including at birth, as infants)?	Yes ..... 1 No ..... 2	
<b>All ages</b>			
23.	Can you read well, a little or not at all?	Well ..... 1 A little ..... 2 Not at all ..... 3	
24.	Are you currently attending/ever attended school?	Yes, still studying ..... 1 Yes, no longer studying ..... 2 No, never ..... 3	<b>2→35</b> <b>3→</b>
25.	What level of education are you in now?	Pre-primary/ECED ..... 1 Primary (grades 1-5) ..... 2 Lower secondary (grades 6-8) ..... 3 Secondary (grades 9-10) ..... 4 Upper secondary (grades 11-12) ..... 5 Post-secondary/university/college ..... 6	<b>5,6→32</b>
<b>For children currently in school (up to and including upper secondary)</b>			
26.	What grade/class are you enrolled in?	Grade: _____	
27.	Are you enrolled in the same class as other children your age?	Yes, same ..... 1 No, lower grade than other children ..... 2 No, higher grade than other children ..... 3	
28.	[For children with disabilities]: Is the school you are in a mainstream/regular school or special school?	Mainstream/regular ..... 1 Integrated (both children with and without disabilities can attend; but separate classes/extra resources for child with disabilities) ..... 2 Special school (only children with disabilities attend) ..... 3	
29.	In the last month of school, how many days did you miss?	Number of days: _____	

<sup>24</sup> Some questions adapted from World Bank Living Standard Measures (Grosh, M.E. and J. Muñoz, A manual for planning and implementing the living standards measurement study survey. 1996: The World Bank.)

Q. #	Question	Codes	Go to Q
30.	Have you ever repeated a class at school?	Yes..... 1 No ..... 2	2→32
31.	How many times have you repeated a class at school?		
<b>For all participants currently in school (Q24=1)</b>			
32.	Do you receive government scholarships?	Yes..... 1 No ..... 2	2→
33.	How much do you receive?	NPR _____	
34.	Why are you receiving this scholarship	Child with a disability.....1 Dalit.....2 For girls.....3	
<b>For participants who went to school in the past (Q24=2)</b>			
35.	What is the highest level of education you completed?	Some primary (<grade 5)..... 1 Primary (grade 5 completed)..... 2 Lower secondary (grade 8 completed)..... 3 Secondary (SLC completed) ..... 4 Upper secondary (grade 12 completed).....5 Post-secondary (e.g. BA or equivalent completed)..... 6	
36.	What was the highest class that you completed?	Class completed: _____	
37.	What is the main reason why you did not go to school/stopped when you did?	Finished as expected (met education goals)..1 Lack of money..... 2 Needed to work (outside of home) ..... 3 Needed to work (inside home/for family).... 4 Not admitted/expelled due to disability.....5 Not admitted/expelled for other reason.....6 No nearby school.....7 No transport, difficult to travel to school..... 8 School inaccessible (facilities, teaching) for person with my type of disability.....9 Negative experience (e.g. bullying)..... 10 Married, had a child.....11 Illness/too sick.....12 Family does not allow..... 13 Education I was receiving not very useful ... 14 Don't like school/not interested in going .... 15 Other (specify) ..... 16	
<b>Ask this question about head of the household (if he/she is <u>NOT</u> the study subject) (Q11=2)</b>			



Q. #	Question	Codes	Go to Q
38.	What is the highest level of education [name] completed?	Below primary (< grade 5) ..... 1 Primary (grade 5 completed)..... 2 Secondary (SLC completed) ..... 3 Upper secondary (grade 12 completed)..... 4 University (BA or equivalent completed) ..... 5 No education ..... 6	
39.	Can [name] read well, a little or not at all?	Well..... 1 A little ..... 2 Not at all ..... 3	

### Section 3: Work & Livelihoods<sup>25</sup> (Respondents 15+, who are not in education currently)

**Note to interviewer: If answered by proxy replace "are you" with "is [name]"**

**I would now like to ask you some questions about work**

40.	Other than domestic work in the household, have you done any work in the last seven days?	Yes..... 1 No ..... 2	1→43
41.	Although you did not work in the last seven days, do you have any job or business from which you were absent for leave, illness, vacation, or any other such reason?	Yes..... 1 No ..... 2	1→43
42.	Have you done any work in the last 12 months?	Yes..... 1 No ..... 2	2→49
43.	What is your occupation, that is, what kind of work do you mainly do?	Farming/animal husbandry ..... 1 Small business owner ..... 2 Civil servant (work for the government) ..... 3 Teacher ..... 4 Health worker ..... 5 Other (specify) ..... 6	
44.	Do you do this work for: (Read All)	Family member..... 1 Someone else (e.g. business) ..... 2 Government ..... 3 Self-employed.....	
45.	During the last 12 months, how many months did you work?	Months: _____	
46.	Do you usually work throughout the year, or do you work seasonally, or only once in a while?	Throughout the year ..... 1 Seasonally/part of the year ..... 2 Only once in a while..... 3	

<sup>25</sup> Some questions adapted from World Bank Living Standard Measures (Grosh, M.E. and J. Muñoz, A manual for planning and implementing the living standards measurement study survey. 1996: The World Bank.)

47.	Are you paid in cash or kind for this work or are you not paid at all?	Cash only ..... 1 Cash and kind ..... 2 In kind only..... 3 Not paid ..... 4	3, 4 →49
48.	If paid in cash, how much do you earn on average in a month?	NPR: _____	→ 49
49.	Have you received job/vocational training or livelihood support (e.g. inputs for farming, training in farming techniques) in the last two years?	Yes..... 1 No ..... 2	
50.	If not working, what is the main reason?	Retired ..... 1 Retrenched (due to cutbacks) ..... 2 Fired..... 3 No jobs opportunities ..... 4 Childcare/duties/work inside the house ..... 5 Incapable of working, physically..... 6 Incapable of working, mentally ..... 7 Nobody would give me a job because I am disabled..... 8 Illness ..... 9 Injury/accident at work..... 10 Other (specify) ..... 11	

**Questions 51-59 used in Nepal only<sup>26</sup>**

	In the past 12 months _____	Never	Rarely	Someti mes	Often	
51.	How frequently did you worry that your households would not have enough food?	1	2	3	4	
52.	How often were you or any household member not able to eat the kinds of foods you preferred because of a lack of resources?	1	2	3	4	
53.	How often did you or any household member have to eat a limited variety of foods due to lack of resources?	1	2	3	4	
54.	How often did you or any household member have to eat a smaller meal than you felt you needed because there was not enough food?	1	2	3	4	
55.	How often did you or any household member eat fewer meals in a day because of a lack of resources to get food?	1	2	3	4	
56.	How often was there no food to eat of any kind in your household because of lack of resources to get food?	1	2	3	4	
57.	How often did you or any household member go to sleep at night hungry because there was not enough food?	1	2	3	4	

<sup>26</sup> USAID's Household Food Insecurity Access Scale: Coates, J., A. Swindale, and P. Blilinsky, *Household Food Insecurity Access Scale (HFIAS) for Measurement of Food Access: Indicator Guide* 2007, USAID: Washington, D.C

58.	Did the household have to adopt the following to meet the household food needs in the last 12 months:	Yes	No	
	1. Take out a loan	1	2	
	2. Sell household assets	1	2	
	3. Sell livestock	1	2	
	4. Sell land	1	2	
	5. Probe: any other steps taken?	If yes, specify:		
59.	What was the cause of the food shortage in your household in the last 12 months?	Crop failure ..... 1 Flood ..... 2 Drought ..... 3 Landslide ..... 4 Financial problems ..... 5 No food in market ..... 6 Other (specify) ..... 7		

## Section 4: Household Expenses

I am now going to ask you some questions about household expenses. NOTE to interviewers  
- if interviewee is not sure, ask household head

Q. #	Question	Codes	
<b>A</b>	<b>Healthcare Expenses: over the past month has your household spent money on any of the following (out of pocket)? (Read All)</b>		
60.	Hospital/Clinic Costs: e.g. fees to see a Dentists/Doctor/Nurse/other health care worker	Yes ..... 1 No ..... 2	1→63
61.	Medical Supplies: Medicines, Bandages	Yes ..... 1 No ..... 2	1→64
62.	Natural/Traditional/Complementary Therapy	Yes ..... 1 No ..... 2	1→65
63.	How much did the household spend on hospital/clinic costs over the past month?	NPR	
64.	How much did the household spend on natural/traditional/complementary therapy over the past month?	NPR	
65.	How much did the household spend on medical supplies over the past month?	NPR	
66.	In the past <b>year</b> have your household spent money on medical insurance fees?	Yes ..... 1 No ..... 2	→B
67.	How much did the household spend on medical insurance over the past year?	NPR	
<b>B</b>	<b>Education fees: Over the past month has your household spent money on the following? (Read All)</b>		

Q. #	Question	Codes	
68.	Primary/secondary/high school fees and Tuition	Yes .....1 No .....2	1→71
69.	University Fees	Yes .....1 No .....2	1→72
70.	Other School Expenses (books, boarding transport, meals at school)	Yes .....1 No .....2	1→73
71.	How much did the household spend on primary/secondary/high school fees over the past year?	NPR	
72.	How much did the household spend on university fees over the past year?	NPR	
73.	How much did the household spend on other school expenses over the past year?	NPR	
<b>C</b>	<b>Transportation: In the past 7 days, has any member of your household spent money on any of the following items? (Read All)</b>		
74.	Fares for public transport (buses, taxis, rickshaw etc.)	Yes .....1 No .....2	1→77
75.	Petrol, oil and car/motorbike service	Yes .....1 No .....2	1→78
76.	Parking	Yes .....1 No .....2	1→79
77.	How much did the household spend on fares for public transport over the past 7 ?	NPR	
78.	How much did the household spend on fares for petrol/oil and car/motorbike service over the past 7 ?	NPR	
79.	How much did the household spend on parking over the past 7 ?	NPR	

## Section 5: Social Protection

I am now going to ask you about your participation in certain government programmes.

A	80. Have you heard of this programme: 1=Yes 2=No (go to next programme)	For each programme where 80=1		If 82=1	If 83=1, 2	If 83=3	If 84=2
	Name of programme	81. How did you hear about it? 1=Programme staff 2=NGO 3=DPO 4=Media 5=Health facility 6=Government 7=Friend/family	82. Are you or anyone else in this household eligible? 1=Yes 2=No	83. Have you or another household member ever participated? 1=Yes, I have 2=Yes, another household member 3=No one in the household	84. Are you/they currently participating? 1=Yes 2=No	85. If you/they are eligible but not participating, why are you/they not participating? 1=Applied but denied 2=I didn't think eligible 3=Lack of information on how to apply 4=Lacked needed documentation 5=Application office too far/lack transportation 6=Application office/process inaccessible 7=Discrimination by programme staff 8=Application took too much time	86. If you reported once participating but are not now, why are you/they no longer participating? 1=Reapplied but denied 2=No longer eligible/don't think eligible 3=Lack of information on how to reapply 4=Took too much time to reapply 5=Lacked needed documentation 6=No longer need the programme 7=Missed deadline 8=Application office too far/lack transportation 9=Not satisfied with the programme
a	Disability Pension	1 2					
b	Old Age Allowance	1 2					
c	Single Women (widow) Allowance	1 2					
d	Pensions/compensation for people who become disabled through work, in times of conflict or while serving in the army	1 2					
e	Child protection grant (for poor Dalit children under 5)	1 2					

<b>B</b>	<b>For each programme that household member participates in:</b>	85. For how long have you been in the programme? (state in years)	86. Do you have to pay any fees, make any financial contribution in order to participate? 1=Yes; 2=No	87. Does the program offer health insurance? 1=Yes; 2=No	88. What kinds of benefits are received from the programme ? 1=Cash; 2=in-kind 3=Both	89. How often do you receive benefits? 1=Monthly 2=2-6x per year 3=Annually 4=Less than annually	90. If cash, how much is received in each installment? (NPR)	91. Are you satisfied with the programme? 1=Yes 2=No 3=Neutral
a	Disability Pension							
b	Old Age Allowance							
c	Single Women (widow) Allowance							
d	Pensions/compensation for people who become disabled through work, in times of conflict or while serving in the army							
e	Child protection grant (for poor Dalit children under 5)							

<b>C</b>	<b>What type of impact, if any, has participation in these programmes had on...</b>	Large positive	Some positive	No change	Some negative	Large negative
92.	Ability to meet the basic food needs of the household	1	2	3	4	5
93.	Ability to pay for non-food household expenses	1	2	3	4	5
94.	School attendance of children in household	1	2	3	4	5
95.	Your ability to get medical care when you need it	1	2	3	4	5
96.	Other members of your household's ability to get medical care when they need it	1	2	3	4	5
97.	Your ability to work, earnings	1	2	3	4	5
98.	Other household members' ability to work, earnings	1	2	3	4	5
99.	Household savings	1	2	3	4	5
100.	Your participation in community/social activities	1	2	3	4	5
101.	Other household members' participation in community/ social activities	1	2	3	4	5

## Section 6: Health and Antenatal Care<sup>27</sup>

*I'm now going to ask you some questions about your health and any difficulties you may have or be facing.*

Q. #	Question	Codes	Go to Q
<b>F1</b>	<b>Cases only (all ages)</b>		
	Note to Interviewer: If participant screened positive via self report say:		
	<b>Your responses to our earlier questions and examinations indicate that you may have difficulties in certain areas related to your health.</b>		
102.	What do you think is the cause of the difficulties you face in your health? (tick all that apply)	From Birth..... 1 Trauma..... 2 Illness ..... 3 Aging ..... 4 Witchcraft, curse, supernatural..... 5 Other..... 6	
103.	How old were you when it started?	Years: _____	
<b>F2</b>	<b>ALL CASES AND CONTROLS</b>		
104.	How would you evaluate your <u>current</u> health?	Very good ..... 1 Good ..... 2 Medium ..... 3 Weak..... 4 Very weak..... 5	
105.	Do you have health insurance?	Yes..... 1 No ..... 2	<b>2→108</b>
106.	What type of costs does this health insurance cover?	Fees for visit (general healthcare) ..... 1 Fees for visit (specialist services) ..... 2 Medications ..... 3 Assistive devices ..... 4 Transport to/from health facility..... 5 Accommodations ..... 6 Fees for tests ..... 7 Don't know ..... 8	
107.	In the last 30 days, have you smoked tobacco (e.g. cigarette, bidi, pipe)?	Yes..... 1 No ..... 2	
108.	108.1 Have you ever been tested for diabetes (e.g. had blood tests where they test your blood sugar level)?	Yes..... 1 No ..... 2	
	108.2. Have you ever been diagnosed with diabetes (high blood sugar)?	Yes..... 1 No ..... 2	<b>2→108.5</b>
	108.3 If yes, have you ever been treated for it (e.g. insulin or other blood sugar lowering medication, special diet/exercise plan)?	Yes..... 1 No ..... 2	<b>2→108.5</b>

<sup>27</sup> Questions for World Health Surveys (World Health Organization. World Health Survey Instruments and Related Documents. 2002 [cited 2019 March 29]; Available from: <https://www.who.int/healthinfo/survey/whslonghouseholdlow.pdf?ua=1>.); Demographic and Health Surveys (Ministry of Health and Population [Nepal], New ERA, and ICF International Inc, *Nepal Demographic and Health Survey 2011*, M.o.H.a. Population, Editor. 2012: Kathmandu, Nepal); and World Bank Living Standard Measures (Grosh, M.E. and J. Muñoz, A manual for planning and implementing the living standards measurement study survey. 1996: The World Bank.)

Q. #	Question	Codes	Go to Q
	108.4 Are you currently (as of the past 2 weeks) on treatment?	Yes..... 1 No ..... 2	
	108.5. Have you ever been tested for hypertension (had blood pressure measured)?	Yes..... 1 No ..... 2	
	108.6 Were you diagnosed with hypertension?	Yes..... 1 No ..... 2	<b>2→108.9</b>
	108.7 If yes, have you ever been treated for it (medications, diet/exercise plan)?	Yes..... 1 No ..... 2	<b>2→108.9</b>
	108.8 Are you currently (as of the past 2 weeks) on treatment?	Yes..... 1 No ..... 2	
	108.9 In the past 12 months, have you ever experienced wheezing, whistling breathing, shortness of breath without an obvious cause (e.g. not after doing physical activity)?	Yes..... 1 No ..... 2	
	108.10 Have you ever been tested for asthma (e.g. had tests that measured how much and how fast you can blow air out of your lungs)?	Yes..... 1 No ..... 2	
	108.11 Have you ever been given a diagnosis of asthma?	Yes..... 1 No ..... 2	<b>2→108.14</b>
	108.12 If yes, have you ever been treated for it (e.g. inhaler)?	Yes..... 1 No ..... 2	<b>2→108.14</b>
	108.13 Are you currently (as of the past 2 weeks) on treatment?	Yes..... 1 No ..... 2	
	108.14 In the past 12 months, have you had a cough that lasted 3 weeks or longer, had blood come up when you coughed?	Yes..... 1 No ..... 2	
	108.15 Have you ever been tested for tuberculosis (e.g. has a doctor taken a sample of substance spit out of a deep cough; taken an X-ray of your chest)?	Yes..... 1 No ..... 2	
	108.16 Have you ever been diagnosed with tuberculosis?	Yes..... 1 No ..... 2	<b>2→109</b>
	108.17 Did you complete your treatment for tuberculosis (or currently in treatment)?	Yes..... 1 No ..... 2	
109.	Have you had any <u>serious</u> health problems during the last twelve months?	Yes..... 1 No ..... 2	<b>2→112</b>



110.	If yes, what type of serious health event(s) or problem(s) did you experience during this period? (tick all that apply)	Severe Diarrhea (with dehydration or for more than 14 days)..... 1 Acute respiratory tract infection/pneumonia ..... 2 Heart problems..... 3 Eye Infection/eye problems ..... 4 Ear infection/ear or hearing problems ..... 5 Malnutrition ..... 6 Vaccine-preventable disease ( <i>including measles, typhoid, chickenpox, mumps, rubella, tetanus, whooping cough</i> )..... 7 Tuberculosis ..... 8 Chronic Illness..... 9 Accident/Injuries ..... 10 Don't know/ no information provided ..... 11 Other (specify)_____ ..... 12																														
111.	Did you or someone on your behalf seek treatment/advice)?	Yes..... 1 No ..... 2		<b>2→119</b>																												
112.	Where did you seek advice or treatment?	<i>Government sector</i> Government hospital/clinic ..... 1 Primary health care centres ..... 2 Health post/subhealth post..... 3 Mobile clinic ..... 4 <i>Private sector</i> Private clinic/hospital/doctor..... 5 Pharmacy ..... 6 Traditional healer ..... 7 <i>NGO service</i> ..... 8 Female community health volunteer ..... 9 Other (specify)_____ ..... 10																														
113.	Did you require any of the following and if so, how much did you have to pay, if any?	<table border="1"> <thead> <tr> <th colspan="2">Required?</th> <th rowspan="2">If required, how much did it cost?</th> </tr> <tr> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td>1. Fees for visit</td> <td>1</td> <td>2</td> <td></td> </tr> <tr> <td>2. Medications/equipment/devices</td> <td>1</td> <td>2</td> <td></td> </tr> <tr> <td>3. Transport to/from facility</td> <td>1</td> <td>2</td> <td></td> </tr> <tr> <td>4. Accommodations (if had to stay overnight, in either facility or nearby)</td> <td>1</td> <td>2</td> <td></td> </tr> <tr> <td>5. Fees for tests</td> <td>1</td> <td>2</td> <td></td> </tr> <tr> <td>6. Probe: were there any other costs?</td> <td>1</td> <td>2</td> <td></td> </tr> </tbody> </table>	Required?		If required, how much did it cost?	Yes	No	1. Fees for visit	1	2		2. Medications/equipment/devices	1	2		3. Transport to/from facility	1	2		4. Accommodations (if had to stay overnight, in either facility or nearby)	1	2		5. Fees for tests	1	2		6. Probe: were there any other costs?	1	2		
Required?		If required, how much did it cost?																														
Yes	No																															
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2. Medications/equipment/devices	1	2																														
3. Transport to/from facility	1	2																														
4. Accommodations (if had to stay overnight, in either facility or nearby)	1	2																														
5. Fees for tests	1	2																														
6. Probe: were there any other costs?	1	2																														
114.	[Total amount paid – automatically calculated, but confirm with respondent]																															
115.	How did you pay for this treatment the last time you sought treatment? [select all that apply]	Paid with current income ..... 1 Paid with savings ..... 2 Paid with insurance ..... 3 Paid by selling items ..... 4 Paid by borrowing ..... 5 Family paid ..... 6 Other, specify ..... 7																														

116.	How would you rate your satisfaction with the services received?	Very satisfied ..... 1 Fairly satisfied ..... 2 Neutral ..... 3 Fairly dissatisfied ..... 4 Very dissatisfied ..... 5	
117.	If you did not seek advice or treatment, what was the reason? (check all that apply)	Went to facility, but did not receive treatment ..... 1 Financial reasons ..... 2 Health facility too far ..... 3 No transportation available ..... 4 I couldn't take time away from work/school/other responsibilities ..... 5 No one was available to accompany me to take me ..... 6 I didn't know where to go for the services/medication/etc I required ..... 7 Negative attitudes of health staff ..... 8 Didn't think medical treatment needed ..... 9 Other, specify ..... 10	All but 1 → 119
118.	Why did you not receive treatment when you went to the facility?	Medications, equipment not available ..... 1 Service, staff not available ..... 2 I was refused because I was disabled ..... 3 I was refused for other reasons ..... 4 Don't know ..... 5 Other (specify) ..... 6	
Consider the nearest health facility where you could receive health care in the event of an emergency			
119.	a. How long would it take you to reach this facility (ONE WAY)?	Less than 30 minutes ..... 1 30 min-1 hour ..... 2 1 hour-less than 2 ..... 3 2 hours or more ..... 4	
120.	b. What method of transport would you use?	Walk ..... 1 Car/motorbike ..... 2 Bicycle ..... 3 Bus ..... 4	

## Section 7: Participation<sup>28</sup>

**I'm going to ask you some questions about your involvement in different aspects of family, social life and society. Please listen to each one and answer yes, no, sometimes, sometimes or not applicable.**

Q. #	Question	Codes					Go to Q
		Yes	No	Sometimes	N/A	Don't know	
121.	Are you consulted about making household decisions?	1	2	3	4	5	
122.	Do you go with the family to events such as family gatherings, social events, etc?	1	2	3	4	5	
123.	Do you feel involved and part of the household or family?	1	2	3	4	5	
124.	Does the family involve you in conversations?	1	2	3	4	5	
125.	CASES: Does the family help you with daily activities/tasks?	1	2	3	4	5	"No, DK, N/A" →127
126.	CASES: Do you appreciate it or like the fact that you get this help?	1	2	3	4	5	
127.	Do you/did you take part in your own traditional practices (e.g initiation ceremonies)?	1	2	3	4	5	
128.	CASES: Are you aware of organizations for people with disabilities (DPO)?	1	2				"No" →130
129.	CASES: Are you a member of a DPO?	1	2				
130.	Do you participate in local community meetings?	1	2	3	4	5	"No" →132
131.	Do you feel your voice is being heard?	1	2			5	
132.	Did you vote in the last election?	1	2			5	"No"→ sect 8
133.	CASES: Was it related to your disability that you didn't vote?	1	2			5	

<sup>28</sup> SINTEF Participation Scale: Eide, A., S. Neupane, and K.G. Hem, *Living conditions among people with disability in Nepal*. 2016, SINTEF

## Section 8: Well-Being & Stigma

Q. #	Question	Codes					Go to Q
	In the last 6 months, how often...	All of the time	Most of the time	Some of the time	Never	Don't know	
134.	Have you been confident to do new things (e.g. something you have never done before)?	1	2	3	4	5	
135.	Have you enjoyed life?	1	2	3	4	5	
136.	Have you been respected by the community the same way as others?	1	2	3	4	5	
137.	Has your opinion counted in family discussions?	1	2	3	4	5	
138.	Have you felt your life has been meaningful?	1	2	3	4	5	
139.	How often have you felt safe in your daily life?	1	2	3	4	5	
140.	Have you been able to maintain family relationships?	1	2	3	4	5	
141.	How often have you been able to make new friends?	1	2	3	4	5	
142.	How often have you been able to interact with persons of authority?	1	2	3	4	5	
143.	How often have you been able to take care of yourself?	1	2	3	4	5	
144.	Have you been able to take care of your household?	1	2	3	4	5	
145.	How often have your living conditions been as good as for the rest of your household?	1	2	3	4	5	
146.	How often have you had the opportunity to help other people (e.g. neighbours, friends, relatives)?	1	2	3	4	5	
In the past 12 months... <sup>29</sup>							
147.	Have you been beaten, scolded or discriminated against by any household member or relatives?	Yes ..... 1 No ..... 2					
148.	Have you been beaten, scolded, discriminated against at work or school?	Yes ..... 1 No ..... 2					
149.	How often did you experience prejudice or discrimination (anywhere)?	All the time ..... 1 Sometimes ..... 1 Never ..... 1 Don't know ..... 1					

<sup>29</sup> SINTEF questions on violence and discrimination: Eide, A., S. Neupane, and K.G. Hem, *Living conditions among people with disability in Nepal*. 2016, SINTEF

Q. #	Question	Codes	Go to Q
150.	CASES ONLY: in the past 12 months, how often have you experienced prejudice or discrimination <u>because of your disability</u> ?	All the time ..... 1 Sometimes ..... 1 Never ..... 1 Don't know ..... 1	

## Section 9: WASH (Vietnam version)

Q. #	Question	Codes	Go to Q
151.	In the last 6 months, have you experienced difficulty in access to safe drinking water?	Yes ..... 1 No ..... 2	2→153
152.	What is the main reason why?	None available in my area ..... 1 Costs of access ..... 2 Difficulty to getting to safe water supplies (e.g. pumps, taps, wells) from home by myself ..... 3 Family has difficulty assisting you in accessing safe water (e.g. bringing you safe water, helping you collect safe water) ..... 4 Negative attitudes towards you if you try to access ..... 5 Other, specify ..... 6	
153.	In the past 6 months, have you had difficulty accessing toilet facilities?	Yes ..... 1 No ..... 2	2→Sect 10
154.	If yes, what is the main reason why?	None available in my area ..... 1 Costs of access ..... 2 Difficulty in getting to/using toilet facilities by myself ..... 3 Family has difficulty assisting you in accessing toilets(e.g. bringing you to toilet facilities, helping you to use) ..... 4 Negative attitudes towards you if you try to access ..... 5 Don't know ..... 6 Other, specify ..... 7	

## Section 9: WASH (Nepal version) – for people aged 15+ only<sup>30</sup>

I would like to ask you some questions about your water use, your bathing, your handwashing and your defecation practices. The questions refer to what you do most of the time when you are at home. I'm going to begin with some questions about your water use.

Q. #	Question	Codes	Go to Q
<b>WATER USE</b>			
155.	Who mainly collects water in your community? Read option – more than one can be ticked if appropriate)	Men..... 1 Women ..... 2	
156.	In your community what age are the people who normally collect water? (read options - more than one can be ticked if appropriate)	Under 15 years of age..... 1 15-50 years of age ..... 2 Over 50 years of age ..... 3	
157.	Where is this water source located?	In own dwelling..... 1 In own yard/plot ..... 2 Elsewhere ..... 3	1→162
158.	Do you ever go to collect water	Yes ..... 1 No ..... 2	2→163
159.	When you go to collect water do you need help from others?	Yes ..... 1 No ..... 2	
160.	Do you collect water from the same sources(s) as other members of your household?	Yes ..... 1 No ..... 2	
161.	Does collecting water cause you any additional pain?	Yes ..... 1 No ..... 2	
162.	Are you afraid of physical or verbal abuse or violence when you collect water?	Yes ..... 1 No ..... 2	
163.	Can you access stored water in your home without help from others?	Yes ..... 1 No ..... 2	
<b>BATHING</b>			
164.	Do you usually need help from others when you go for bathing?	Yes ..... 1 No ..... 2	
165.	81. When are at home where do you usually bathe?	In house, compound, yard..... 1 At tap or pump, away from compound ..... 2 At surface water source away from compound (stream/river/pond/lake etc) ..... 3	
166.	Do you use the same place for bathing as other adult members of your household?	Yes ..... 1 No ..... 2	
167.	Does it cause you additional pain to use this place (more pain than you normally feel)?	Yes ..... 1 No ..... 2	
168.	Do you use this place with as much privacy as other people?	Yes ..... 1 No ..... 2	
169.	Are you afraid of physical or verbal abuse or violence when you use this place?	Yes ..... 1 No ..... 2	
170.	Do you use this place without coming into contact with dirt or dirty water?	Yes ..... 1 No ..... 2	

<sup>30</sup> Quality of WASH tool (Kuper, H., et al., Exploring the links between water, sanitation and hygiene and disability; Results from a case-control study in Guatemala. PloS one, 2018. 13(6): p. e0197360.)

Q. #	Question	Codes	Go to Q
<b>HANDWASHING</b>			
171.	Are you able to wash your hands without help from others?	Yes .....1 No .....2	
172.	Are you able to locate and use soap or other cleansing materials without help from others?	Yes .....1 No .....2	
<b>MENSTRUATION (FEMALES ONLY)</b>			
173.	When you are menstruating, do you get blood on your clothing?	Yes .....1 No .....2	
<b>SANITATION</b>			
174.	Do you usually need help from others when you for defecation?	Yes .....1 No .....2	
175.	When you are at home where do you usually go for defecation (read options)	In the bush, field .....1 In chamber pot/bucket at house .....2 Toilet/latrine owned by household.....3 Toilet/latrine owned by neighboring household .....4 Public toilet.....5	
176.	Does it cause you additional pain to use this place?	Yes .....1 No .....2	
177.	Is this the same place that other adults in your household usually use for defecation?	Yes .....1 No .....2	
178.	Do you use this place without coming into contact with faeces or urine?	Yes .....1 No .....2	
179.	When you go for defecation do you have as much privacy as other members of your household?	Yes .....1 No .....2	
180.	Are you afraid of physical or verbal abuse or violence when you go for defecation?	Yes .....1 No .....2	

## Section 10: REHABILITATION & ASSISTIVE DEVICES - Cases only<sup>31</sup>

I am now going to ask you some questions about some services specifically for people with disabilities that you may or may not have heard of or have used now or in the past

		181.1. Have you ever heard of this type of service? 1= Yes 2= No→ Go to next service	181.2 Have you ever needed this service? 1= Yes 2= No→ Go to next service	181.3 Have you ever received this service? 1= Yes →1.4 2= No→1.6	181.4 Who did you receive this service from?  1=Governme nt provider 2=Private 3=NGO 4=Don't know 5=Other	181.5 If yes, are you currently receiving or using it?  1= Yes →1.8 2= No→1.7	181.6 If reported needing (Yes to Q1.2) but not receiving a service (No to Q1.3), why have you not received it?  1 = Too expensive 2 = Too far/no transport 3 = Discriminating 4 = Communication barriers 5 = Don't know where to access 6 = Service not available 7= Other (specify)____ <b>up to three responses allowed (Go to next service)</b>	181.7 If reported once receiving/using service (Yes to Q1.3) but not receiving it now (No to Q1.5), ask why are you no longer receiving it?  1 = Too expensive 2 = Too far/no transport 3 = No longer available 4 = Communication/language barriers 5 = Don't know where to access 6 = Not really helping me 7 = Not satisfied with services 8= No longer need the service 9=Broken and unable to repair <b>up to three responses allowed</b>	181.8 If reported once receiving/ using service (Yes to Q1.3 or Q1.5), who paid?  1= I paid fully 2 = Health insurance part, I paid part 3 = Health insurance paid in full 4= Service was free	181.9 If Paid out of pocket, what was the amount
a	<b>Medical rehabilitation</b> (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	1    2	1    2	1    2		1    2				
b	<b>Assistive devices service</b> (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	1    2	1    2	1    2		1    2				
c	<b>Specialist educational services</b> (e.g. therapist, school support services)	1    2	1    2	1    2		1    2				
d	<b>Vocational Training</b> (e.g. Employment skills training, etc.)	1    2	1    2	1    2		1    2				
e	<b>Counselling for person with a disability</b> (e.g. Psychologist, psychiatrist, counsellor)	1    2	1    2	1    2		1    2				

<sup>31</sup> Adapted from SINTEF Living Conditions Survey; Eide, A., S. Neupane, and K.G. Hem, *Living conditions among people with disability in Nepal*. 2016, SINTEF



## Appendix 5: Disability Allowance questionnaire<sup>32</sup>

### SOCIAL PROTECTION & DISABILITY STUDY Disability Allowance Questionnaire, 2016

A: Cover Sheet		
1	Date (Day/Month/Year):	
2	Cluster name	
3	Cluster No.	
4	House No.	
5	Subject No.	
6	Interviewer No.	
7	Age of Disability Allowance recipient	Age : _____
8	Gender of Disability Allowance recipient	Male .....1 Female .....2
9	Was this person recruited from case control study or Disability Allowance registers?	From case control study .....1 From register .....2

	Question	Codes	Go to Q
	<b>Disability Grant QUESTIONNAIRE</b>		
1	Do you have a disability card? [Confirm]	Yes .....1 No .....2	
2	What category?	Red .....1 Blue .....2 Yellow .....3 White .....4	
3	How long have you had the disability card for?	Less than 6 months .....1 Between 6 months and 1year .....2 Between 1 year and 5 years .....3 More than 5 years .....4	

<sup>32</sup> This is the questionnaire used in Nepal. The questionnaire used in Vietnam is similar, with some context-specific differences.

	Question	Codes	Go to Q
4	How did you learn about the disability card?	VDC/ward officials .....1 District government officials.....2 Health professional.....3 DPO .....4 NGO .....5 Media (radio, TV, newspaper, etc) .....6 Friend/family .....7 Other.....8	
5	Where did you go to apply for the disability card? (tick all that apply)	Registration camp.....1 Women and Children's Development Office.2 District distribution committee .....3 VDC/ward.....4 Other .....5	
6	As part of the application process, did you have a medical assessment (meaning, did doctors or a health professional exam you)?	Yes.....1 No .....2	→9
7	Overall how satisfied were you with the assessment process?	Very.....1 Somewhat.....2 Neutral.....3 Unsatisfied .....4 Very unsatisfied .....5 n/a.....6	
8	How satisfied were you with the respectfulness of the assessment process?	Very.....1 Somewhat.....2 Neutral.....3 Unsatisfied .....4 Very unsatisfied .....5 n/a.....6	
9	How many trips in total were required to complete the application?	Number of trips:_____	
10	Did you have to pay anything to register for the card?	Yes.....1 No .....2	→12
11	If yes, how much did you pay?	NRs._____	
12	Do you feel you have been placed in the right disability category?	Yes.....1 No, should be in a higher (for more severe disability) .....2 No, should be in lower (for less severe disability) .....3	
13	During the application process, how would you describe your experience of the following?	<b>No difficulty</b> <b>Some difficulty</b> <b>A lot of difficulty</b>	<b>n/a</b>
	a. Getting to application office (or other application points)	1      2      3	4

	Question	Codes			Go to Q
	b. Accessibility of facilities or application points	1	2	3	4
	c. Understanding the application process	1	2	3	4
	d. Gathering the necessary documents for the application	1	2	3	4
	e. Communicating with programme staff/officials	1	2	3	4
	f. Attitudes of programme staff	1	2	3	4
	g. Meeting application deadlines	1	2	3	4
	h. Receiving disability assessment	1	2	3	4
	i. Paying for transport	1	2	3	4
14	If you faced difficulties during the application process, which would you say was the most significant?				
15	As someone with a disability card, are you...	a. Eligible for any of the following?  1=Yes 2=No→next benefit 3=Don't know → next benefit	b. Receiving this benefit?  1=Yes 2=No→ d	c. Were you receiving this benefit before having a disability card?  1=Yes 2=No [Go to next]	d. If not receiving this benefit that you are eligible for, what is the reason?  1=I don't know how to apply 2=Application is too complicated 3=These benefits wouldn't be helpful for me 4=Applied but denied 5=Other
	<b>1. Disability Allowance (cash payments)</b>				
	2. Public transportation discounts				
	3. Education scholarships				
	4. Tax deductions				
	5. Discounted medicines/other health benefits				
	6. Job training/vocational services/other livelihood support (e.g. agriculture training, inputs)				
<b>(If receiving education scholarship)</b>					
16	What does the education scholarship cover? (check all that apply)	Tuition (up to end of lower secondary/8 <sup>th</sup> grade) .....1 Tuition (secondary and beyond) .....2 Non-tuition school fees (e.g. books, school development funds) .....3 Transportation .....4 Accommodations.....5 Specialist resources (e.g. sign language, braille, teacher's assistant) .....6 Other (specify) .....7			

	Question	Codes			Go to Q
17	Would you be able to meet these costs without the scholarship?	Yes .....1 No .....2 Don't know .....3			
18	Who receives the education scholarship?	Household .....1 School .....2 Other .....3			
<b>Continue for those who are currently receiving the Disability Allowance</b>					
19	After receiving your disability card, how long did it take until you began receiving the Disability Allowance?	Less than a month .....1 1-3 months .....2 4-6 months .....3 7-12 months .....4 More than a year .....5			
20	Did you have to register for the Disability Allowance or were you automatically enrolled once you received your disability card?	Register .....1 Automatically enrolled.....2 Don't know.....3			<b>→23</b> <b>→23</b>
21	Where did you go to register for the Disability Allowance? (tick all that apply)	Registration camp .....1 Women and Children's Development Office .....2 District distribution committee.....3 VDC/ward .....4 Other.....5			
22	How many trips in total were required to complete the application for the Disability Allowance?	Number of trips: _____			
23	How long have you been receiving the disability allowance for?	Less than 6 months .....1 Between 6 months and 1year .....2 Between 1 year and 5 years .....3 More than 5 years.....4			
24	How much do you receive from the Disability Allowance in each installment?	NRs. _____			
25	How many times in a year do you receive payments?	Number of times: _____			
26	After being registered for the disability card/disability allowance...	a) Were you referred to any of these services	b) Did you go to the referred service?	c) If you didn't go to the referred service, what is the reason?	
		1=Yes 2=No 3=Don't know	1=Yes→Go to next 2=No	1=Cost of service unaffordable 2=Other costs (time off work, transport) unaffordable 3=Service locations too far, no accessible transportation 4=I don't think they would be useful 5=I was already accessing the service before the referral	
	1.Rehabilitation services				

	Question	Codes						Go to Q
	2.Health services (general)							
	3.Health services (specialist)							
	4.Job training/vocational services/other livelihood support (e.g. agriculture training, inputs)							
	5.Probe: were there any other services you were referred to? If yes, please specify.							
27	How satisfied are you with:	Very	Somewhat	Neutral	Unsatisfied	Very unsatisfied	N/A	
	1.The amount you receive from the disability allowance	1	2	3	4	5	6	
	2.Frequency/regularity of cash installments	1	2	3	4	5	6	
	3.Collection procedures for receiving benefits	1	2	3	4	5	6	
	4.Distance to collection site	1	2	3	4	5	6	
	5.Conditions attached to receiving Disability Allowance	1	2	3	4	5	6	
	6.Access to other services/discounts linked to the Disability Allowance/disability card	1	2	3	4	5	6	
28	Overall, how satisfied are you with the disability allowance?	Very ..... 1 Somewhat ..... 2 Neutral ..... 3 Unsatisfied ..... 4 Very unsatisfied ..... 5						
29	How are decisions made about how to spend money from the disability allowance?	By me (i.e. disability allowance recipient) alone ..... 1 By me in consult with others ..... 2 By someone else ..... 3						
30	Is the money from the disability allowance mostly spent on:	Your expenses ..... 1 Household expenses ..... 2						
31	What are the TWO MAIN THINGS that the money from the disability allowance is spent on?	Household food expenses ..... 1 Non-food household essential expenses ..... 2 Clothing ..... 3 Rent/accommodations ..... 4 Recreation/entertainment ..... 5 Transport ..... 6 Education ..... 7 Water/electricity ..... 8 Rehabilitation, assistive devices, specialist health services ..... 9 General health services ..... 10 Personal assistant, carer ..... 11 Don't know ..... 12 Other, specify ..... 13						
32	<b>What type of impact, if any, has receiving the disability allowance (and associated benefits) had on: (Read All)</b>	Large positive	Some positive	No change	Some negative	Large negative	N/A	
	1.Ability to meet basic food needs of household							
	2. Ability to pay for non-food household essential expenses							
	3.Non-essential household expenditures							
	4.School attendance of your children							

	Question	Codes					Go to Q
	5.Your education, skill development						
	6.Ability to get medical care when you need it						
	7.Your ability to work						
	8.Other household members' ability to work						
	9.Your relationship with other household members						
	10.Your participation in community/social activities						
	11.Socialization with other people with disabilities						
33	Are you a member of a disabled people's organization?	Yes..... 1 No ..... 2					→ end
34	If yes, why did you join? (Main reason)	To socialise with other people with disabilities ..... 1 Access to services ..... 2 Advocacy to government..... 3 Other ..... 4					

**Thank you for your time and cooperation in answering my questions.**

## Appendix 6: Web appendices to Paper 1

**S1 Table. PRISMA Checklist**

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2-3
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4-5
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5-6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	SI 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-6
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7-8

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7-8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	6-7
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	8
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	n/a
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8-9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	SI-3/4, table 2,3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	SI-4
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	SI-4, table 3
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression)	14-18
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	18-24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	22-23
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	18-24
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	PLOS form



## S2 Table. Summarised extraction table

**Table 1: Summary of studies examining sensory impairments and poverty**

Citation	Study design	Study location (region, income)	Rural/urban	Sample size	Disability specifics and measure	Economic measure	Adjusted	Overview of results	Summary of poverty and disability	Summary disability and work	Risk of bias (sources of bias)
<b>SENSORY (HEARING, VISION)</b>											
<i>ALL AGES</i>											
Ataguba et al (2011)*	CS (population-based)	South Africa (SSA, UM)	Both	–	VI (self-reported)	SES	Yes	Prevalence of VI was disproportionately concentrated among lower SES quintiles (p<0.01)	Positive	–	Low
Béria et al (2007)	CS (population-based)	Brazil (LAC, LM)	Urban	2,445	Disabling hearing impairment (CE, ≥41 dB (age ≥15 years), ≥31 dB (<15 years) in better ear)	Income	Yes	Prevalence of disabling hearing impairment was higher among individuals with incomes below US\$200 compared to those above this threshold (OR =1.55; aOR=1.56 (95% CI: 1.06-2.27))	Positive	–	Low
Dandona et al (2001)	CS (population-based)	India (SA, L)	Both	10,293	Blindness (CE, VA <6/60)	SES	Yes	Increasing prevalence of blindness with worsening SES (p<0.0001); Upper vs extreme lower SES: aOR= 9.72 (95% CI: 2.30–41.0)	Positive	–	Low
Dandona et al (2002)	CS (population-based)	India (SA, L)	Both	10,293	Moderate VI(CE, VA<6/18-6/60)	Income	Yes	Increasing prevalence of blindness with worsening SES (p=0.002): Upper vs extreme lower: 3.03 (95% CI: 1.78 - 5.17)	Positive	–	Low
Freeman et al (2013)	CS (population-based)	Mix (70 countries)	Both	260,958	VI (self-reported difficulty seeing)	Assets	Yes	In low income countries, prevalence of VI lower in highest asset group compared to lowest (aOR: 0.83, 95%CI: 0.72-0.95). Same for middle income countries (aOR: 0.0.69, 95% CI:0 0.61-0.78)	Positive	–	Low
Habtmu et al (2015)	CS (population-based)	Ethiopia (SSA, L)	Rural	200	VI (CE, VA<6/18)	Assets	No	Trichiasis cases were more likely to living in poverty if they had visual impairment, but not significant (OR: 1.71, 95% CI 0.98-2.97)	Non-significant	–	Medium (no adjusting for confounding)
Ho et al (2001)	Ecological (population-based)	Mix (53 countries)	Both	–	Blindness (CE, VA<3/60)	GNP	Yes	Prevalence of blindness is higher in developing countries with lower per capita income.	Positive	–	Medium (potential for ecological fallacy)
Minh et al (2015)	CS (population-based)	Vietnam (EA, LM)	Both	4,224	Vision/hearing (WGSS, at least “some difficulty” seeing)	Income	Yes	Households with members with visual impairment had “extra costs” of 12.7% (95% CI: 4.4-21%) of household income; for hearing 20.1% (9.5-30.6%)	Positive	–	Low
<i>CHILDREN</i>											

Natale et al (1992)*	CS (population-based)	India (SA, L)	Urban	640	Sensory (hearing and visual questions on Ten Questions Questionnaire)	Income	No	Children with sensory impairments were more likely to belong to the lowest social status group compared to the next to lowest (p=0.003)	Positive	—	Medium (validity of economic measure)
Pham et al (2013)	CS	Vietnam (EA, L)	Both	9,882	Vision (WGSS, at least “some difficulty” seeing)	Income	Yes	People with difficulty seeing were less likely to belong to the lowest income quintile compared to the highest (aOR=2.5, 95% CI: 1.39-4.66, p-trend: 0.001)	Negative	—	Low
Taha et al (2010)	CS (school-based)	Egypt (ME, LM)	Both	555	Hearing impairment (CE, ≥20 dB)	SES	No	Children with hearing impairment more likely to be in moderate/low SES group compared to high (p<0.05)	Positive	—	Medium (no adjustment, school-based, no response rate)
<b>ADULTS</b>											
Emamian et al (2011)	CS (population-based)	Iran (ME, UM)	Urban	5,182	VI (CE, 0.3 LogMAR in better eye)	SES	Yes	Prevalence of VI increased with worsening SES (high: 3.6%, medium 7.5%, low 11.1%; p<0.001)	Positive	—	Low
Emamian et al (2013)	CS (population-based)	Iran (ME, UM)	Urban	5,190	Near VI (CE, ≥1.6 M in better eye)	SES	Yes	Prevalence of VI increased with worsening SES (highest vs lowest: OR=3.05 (95% CI: 2.55-3.65), aOR=1.49 (1.20-1.86); highest vs. medium: OR=1.87 (1.55-2.26), aOR=1.2 (0.99-1.46)	Positive	—	Low
Mathenge et al (2012)	CS (population-based)	Kenya (SSA, L)	Both	4,314	Blindness (CE, VA<3/60)	Assets	Yes	No significant difference in asset ownership between people with and without blindness (aOR: 0.5, 95% CI 0.2-1.1, poorest to least poor)	Non-significant	—	Medium (only age adjusted, number of blind in each asset category is low - <15 for 3)
Zainal et al (1998)	CS (population-based)	Malaysia (EA, UM)	Rural	282	VI (CE, VA<6/18)	Income	No	Mean level of income was not significantly differently between adults with and without VI	No-significant	—	Medium (no adjusting, small sample, lack of information on analyses)
<b>OLDER ADULTS</b>											
Cockburn et al (2012)	CS (population-based)	South Africa (SSA, UM)	Urban	2,747	Vision impairment (CE, VA <6/18)	SES	Yes	Prevalence of VI increased with decreasing SES (aP<0.001); poorest to wealthiest SES tertile: OR= 4.5 (95% CI: 1.3-3.9); aOR=3.9 (95%CI: 2.2-6.7)	Positive	—	Low
Kuper et al (2008)	CC (population-based)	Kenya (SSA, L), Philippines (EA, LM), Bangladesh (SA, L)	Both	1,131	VI due to cataract (CE, VA<6/24 in better eye)	1. PCE 2. SES 3. Self-rated wealth	Yes	Increasing prevalence of VI with worsening PCE (test for trend of aORs: Kenya p=0.006, Bangladesh p=0.06, Philippines p=0.002); people with VI were more likely than people without VI to be in the lowest (poorest) quartile of PCE rather than highest (Kenya: aOR= 3.2, 95% CI: 1.2–8.8; Bangladesh: aOR=1.7 95% CI: 1.0–3.0;	Positive	—	Low

Philippines: aOR=2.4, 95% CI: 1.2–4.7); Same pattern for SES index and self-rated wealth											
Ploubidis et al (2013)	CS (population-based)	Kenya	Both	1,402	VI (CE, VA<6/18 in best eye, available correction)	Assets	Yes	Older adults with VI owned significantly fewer assets than older adults without VI in rural areas; no significant difference in urban areas.	Positive, mixed association	–	Low

Study design abbreviations: CC=case control, CS=cross-sectional; Means of assessment abbreviations: CE=clinical evaluation, dB=decibel, VA=visual acuity, VI=visual impairment, WGSS=Washington Group Short Set; Study location: EA=East Asia & Pacific, LAC=Latin America and the Caribbean, ME=Middle East & North Africa, SA=South Asia, SSA=Sub-Saharan Africa, L = low income country, LM=lower middle income country, UM=upper middle income country; Economic measure abbreviation: GNP=gross national product, PCE=per capita expenditure, SES=socioeconomic status; Overview of results abbreviations: CI=confidence interval, OR=odds ratio, aOR=adjusted odds ratio; \*study is repeated in more than one category (results have been disaggregated by disability type)

**Table 2: Summary of studies examining physical impairments and poverty**

Citation	Study design	Study location (region, income)	Rural/urban	Sample size	Disability specifics and measure	Economic measure	Adjusted	Association between disability and poverty	Summary of poverty and disability	Summary disability and work	Risk of bias (sources of bias)
<i>ALL AGES</i>											
Ataguba et al (2011)*	CS (population-based)	South Africa (SSA, UM)	Both	–	Physical impairment (self-reported)	SES	Yes	Prevalence of physical impairment was disproportionately concentrated among lower SES quintiles (p<0.01)	Positive	–	Low
Lin et al (2013)	CS (population-based)	China (EA, LM)	Both	2.6 million	Physical impairment caused by road traffic accidents (CE, ICF, ICD-10)	Income	Yes	Adults: higher prevalence of disability from road traffic accidents among persons with lower family income (aOR= 1.61 (95% CI: 1.43–1.81). Children - no significant difference by income level	Positive	Positive	Low
Minh et al (2015)*	CS (population-based)	Vietnam (EA, LM)	Both	4,224	Movement (WGSS, at least “some difficulty” seeing)	Income	Yes	Households with members with movement difficulty had “extra costs” of 9% (0.5-17.5%)	Positive	–	Low
Rischewski et al (2008)	CC (population-based)	Rwanda (SSA, L)	Both	877	Musculoskeletal impairment (CE, ICF definitions)	1. PCE 2. SES	Yes	No significant difference in PCE or SES among cases with and without physical impairment, except for with boys under 15 years (aOR: 2.2, 95% CI: 1.0-4.4)	Positive	Positive	Low
Sozmen & Unal (2014)*	CS (population-based)	Turkey (ME, UM)	Both	14,433	Arthritis (self-report)	Income	Yes	Arthritis prevalence increased with decreasing wealth (relative index of inequality: 1.36, 1.2-1.54)	Positive	Positive	Low

Wang et al (2015c)	CS (population-based)	China (EA, UM)	Both	21,435	Arthritis (self-report of diagnosis)	Income	Yes	Prevalence of arthritis increased with decreasing income level (lowest to highest group: aOR=0.70 (0.54-0.91))	Positive	–	Medium (validity of disability measure)
<i>CHILDREN</i>											
Ali et al (2013)*	Cohort (population-based)	Pakistan (SA, L)	Urban	420	Fine motor development	Income	Yes	Children from households living below 3,500 rupees/month were more likely to experience delay (aOR: 2.2, 95% CI: 1.4-3.5)	Positive	–	Medium (low response rate, large loss to follow-up)
Jiang et al (2013)*	Cohort (population-based)	Bangladesh (SA, L)	Urban	398	Motor development (Bayley Scales of Infant and Toddler Development)	Income	Yes	Motor scores decreasing with decreasing family income (p=0.007)	Positive	–	Medium (large loss to follow-up, sampling unclear)
Natale et al (1992)*	CS (population-based)	India (SA, L)	Urban	640	Neuromotor (Ten Questions Questionnaire)	Income	No	Children with neuromotor impairments were more likely to belong to the lowest social status group compared to the next to lowest (p=0.005)	Positive	–	Medium (validity of economic measure, no adjusting)
Pham et al (2013)*	CS (population-based)	Vietnam (EA, L)	Both	9,882	Mobility (WGSS, at least "some difficulty")	Income	No	No difference in household income quintile people with and without mobility limitations (p-trend: 0.5)	Non-significant	–	Medium (lack of adjusting)
<i>ADULTS</i>											
Cordeiro de Andre et al (2015)	CS (population-based)	Brazil (LAC, UM)	Both	18,745	Mobility (7 questions on functional limitations)	Income	Yes	No difference in prevalence of mobility limitations between income tertiles	Non-significant	Positive	Low
Hosseinpour et al (2012)*	CS (population-based)	41 countries	Both	170,298	Arthritis (WHS questionnaire, symptom related questions)	SES	Yes	Lower SES correlated with higher prevalence of arthritis (Men: significant in 2/4 models; Women: significant in 1/4 models)	Positive	–	Low
Kilzieh (2010)	CS (population-based)	Syria (ME, LM)	Urban	2,038	Moderate/severe physical impairment (WHS Questionnaire, Health State Descriptions)	SES	Yes	Higher prevalence of physical impairment in poorer SES group Moderate impairment: aOR 1.76 (95%CI: 1.09–2.84) Severe impairment: aOR 2.48 (95% CI: 1.32–4.67)	Positive	Non-significant	Low
Vukovic et al (2008)	CS (population-based)	Serbia (Eur, UM)	Both	14,552	Arthritis (self-report)	SES	Yes	People with arthritis were more likely to belong to the lowest wealth quintile compared to the highest: aOR (men) = 1.59 (95% CI: 1.25-2.02); aOR (women) = 1.41 (95% CI: 1.17-1.72)	Positive	–	Medium (validity of disability measure)
<i>OLDER ADULTS</i>											
Blay et al (2012)*	CS (population-based)	Brazil (LAC, UM)	Both	6,963	Arthritis (self-reported, yes/no to sought treatment in last 6 months)	Income	Yes	Prevalence of arthritis was higher in individuals below the poverty threshold compared to individuals at or above it, but this association was not significant after adjustment	Non-significant	Non-significant	Medium (validity of disability measure)
Falkingham et al (2011)	CS (population-based)	Kenya, (SSA, L)	Urban	2,037	Mobility limitations (WHODAS)	SES	Yes	Adults with mobility limitations were more likely to be from low wealth groups compared to high (p<0.01)	Positive	Non-significant	Low

Fillenbaum et al (2010)	CS (population-based)	Brazil (LAC, UM)	Urban	6,958	Mobility (limitations in activities of daily living)	Income	Yes	People with mobility limitations less likely to have a monthly income over US\$200 (aOR: 0.7, 95% CI: 0.5-0.9)	Positive	–	Medium (validity of disability measure)
Melzer et al (2004)	CS (population-based)	Brazil (LAC, UM)	Both	28,943	Mobility (Questionnaire - difficulties with daily physical activities)	Income	Yes	Lower prevalence of disability in wealthier income groups. Highest vs lowest: aOR (M) = 0.43 (95% CI: 0.35-0.53), aOR (F): 0.72 (95%CI: 0.61-0.84)	Positive	–	Low
Nakua et al (2015)	CS (population-based)	Ghana (SSA, L)	Both	4,724	Arthritis (self-report of diagnosis)	Assets	Yes	People with arthritis were more likely to belong to the wealthiest quintile compared to the poorest (aOR: 1.95, 95% CI: 1.33-2.85)	Negative	–	Medium (validity of disability measure)
Wu et al (2013)*	CS (population-based)	China (EA, UM)	Both	13,157	Arthritis (self-report)	SES	Yes	There was no difference in prevalence of arthritis between the lowest and highest quintile of SES	Non-significant	–	Medium (validity of disability measure)

Study design abbreviations: CC=case control, CS=cross-sectional; Means of assessment abbreviations: CE=clinical evaluation, ICD-10: International Classification of Diseases, ICF: International Classification of Functioning, Disability and Health, WHS: World Health Survey WGSS=Washington Group Short Set; Study location: EA=East Asia & Pacific, Eur=Europe & Central Asia, LAC=Latin America and the Caribbean, ME=Middle East & North Africa, SA=South Asia, SSA=Sub-Saharan Africa, L = low income country, LM=lower middle income country, UM=upper middle income country; Economic measure abbreviation: PCE=per capita expenditure, SES=socioeconomic status; Overview of results abbreviations: OR=odds ratio, aOR=adjusted odds ratio, CI=confidence interval

**Table 3: Summary of studies examining intellectual disability/cognitive impairments and poverty**

Citation	Study design	Study location (region, income)	Rural/urban	Sample size	Disability specifics and measure	Economic measure	Adjusted	Overview of results	Summary of poverty and disability	Summary disability and work	Risk of bias (sources of bias)
<b>ALL AGES</b>											
Ataguba et al (2011)*	CS (population-based)	South Africa (SSA, UM)	Both	–	Intellectual disability (self-reported)	SES	Yes	Prevalence of intellectual disability was disproportionately concentrated among lower SES quintiles ( $p<0.05$ )	Positive	–	Low
Minh et al (2015)*	CS (population-based)	Vietnam (EA, LM)	Both	4,224	Remembering (WGSS, at least “some difficulty”)	Income	Yes	Households with members with remembering difficulty had “extra costs” of 21.1% (11.6–30.6%)	Positive	–	Low
Pham et al (2013)*	CS (population-based)	Vietnam (EA, L)	Both	9,882	Remembering (WGSS, at least “some difficulty”)	Income	No	People with difficulty remembering were more likely to belong to the lowest income quintile compared to the highest ( $p$ -trend: 0.001)	Positive	–	Medium (no adjusting)
<b>CHILDREN</b>											
Escueta et al (2014)*	CC (population-based)	Mix (5 countries)	Both	1,780	Cognitive development delay (KABC-II)	Assets	Yes	Cognitive score increased with increasing wealth ( $p<0.01$ )	Positive	–	Low
Halpern et al (2008)	Cohort (2 x 1 yr, hospital births)	Brazil (LAC, UM)	Urban	5,271	Developmental delay (Denver II Screening Test)	Income	Yes	Prevalence of suspected delay increased with decreasing income ( $p<0.005$ ); highest vs lowest income groups PR (1994): 1.6 (95% CI: 1.2–2.1); PR (2004): 1.4 (95% CI: 1.1–1.8)	Positive	–	Medium (hospital-based)
Jiang et al (2013)*	Cohort (population-based)	Bangladesh (SA, L)	Urban	398	Cognitive and language development (Bayley Scales of Infant and Toddler Development)	Income	Yes	Cognitive and language scores decreasing with decreasing family income (cognitive: $p=0.04$ , language: 0.03)	Positive	–	Medium (large loss to follow-up, sampling unclear)
Kumar et al (1997)	CS (population-based)	India (SA, L)	Rural	3,746	Developmental delay (NP battery, below 25th percentile)	Income	Yes	Higher prevalence of slower psychosocial development in poorer income group: OR=2.30 (95%CI: 1.73–3.05); aOR=1.82 $p=0.011$	Positive	–	Medium (validity of economic measure)
Natale et al (1992)*	CS (population-based)	India (SA, L)	Urban	640	Cognitive impairment (Ten Questions Questionnaire)	Income	No	Children with cognitive impairments were more likely to belong to the lowest social status group compared to the next to lowest ( $p=0.05$ )	Positive	–	Medium (validity of economic measure)
Pheula et al (2011)	CC (public schools)	Brazil (LAC, UM)	Urban	200	ADHD-I (K-SADS-E, CE)	SES	Yes	No significant association	No significant association	–	Medium (school-based)
Xie et al (2008)	CS (population-based)	China (EA, LM)	Both	60,124	Intellectual disability (DDST, Gesell Developmental Inventory)	Income	No	Higher prevalence of ID in children from poorer income group OR=9.54 (95%CI: 4.82–18.91)	Positive	–	Medium (no response rate, no adjusting)

Zheng et al (2012)	CS (population-based)	China (EA, LM)	Both	106,754	Intellectual disability (DDST, Gesell Development Inventory, Vinland Social Maturity Scale)	Income	Yes	Higher prevalence of ID among children in poorer income groups (Mild ID , lowest vs highest: aOR=2.01 (95% CI 1.55-2.82); Severe ID aOR=3.00 (95% CI 2.19-4.12)	Positive	–	Low
<i>OLDER ADULTS</i>											
Arguvanli et al (2015)	CS (population-based)	Turkey (Eur, UM)	Urban	900	Cognitive impairment (MMSE)	Income	Yes	There was no significant difference in income between people with and without cognitive impairment.	Non-significant	–	Medium (sampling strategy unclear and may lead to bias, economic measure unclear)
Chen et al (2011)	Cohort (population-based, 7.5 yr)	China (EA, LM)	Both	1,307	Dementia, incident (AGECAT)	Income	Yes	Incidence of dementia was lower in individuals who reported poor vs satisfactory income, but the difference was not significant	Non-significant	–	Medium (validity of economic measure)
Chen et al (2012)	CS (population-based)	China (EA, LM)	Both	2,917	Dementia, prevalent (GMS/AGECAT)	Income	Yes	Prevalence of dementia was higher among individuals who reported their income as vs satisfactory income, although this association was only significant in Anhui (aOR = 2.18 (95% CI: 1.35-3.51), not the 4 provinces	Positive	–	Medium (validity of economic measure)
Dorsi et al (2011)	CS (population-based)	Brazil (LAC, UM)	Urban	1,692	Cognitive impairment (MMSE)	Income	Yes	Prevalence of cognitive impairment was higher among people from the lowest income quartile compared to the highest: aOR=1.29 (95% CI: 1.09-1.52)	Positive	–	Low
Falkingham et al (2011)*	CS (population-based)	Kenya (SSA, L)	Urban	2,037	Cognition, self-reported functioning (WHODAS)	SES	Yes	Higher wealth status not associated with reporting less problems with cognition (p=ns)	Non-significant	Non-significant	Low
Fei et al (2009)	CS (population-based)	China (EA, LM)	Urban	6,192	Cognitive impairment, no dementia (Interview and NP screens)	Income	Yes	Higher prevalence of cognitive impairment among people with lower income: OR=1.48 (95%CI: 1.25-1.75); aOR=ns	Non-significant	–	Low
Herrera et al (2002)	CS (population-based)	Brazil (LAC, UM)	Urban	1,656	Dementia (MMSE, PFAQ, CE)	SES	Yes	No significant association between dementia and SES was found	Non-significant	–	Medium (analysis unclear)
Keskinoglu (2006)	CS (population-based)	Turkey (Eur, UM)	Urban	201	Dementia (MMSE)	Income	Yes	Higher prevalence of dementia in poorer income group: OR=3.25 (95%CI: 1.21-8.76); aOR=ns	Non-significant	Positive	Medium (small sample, that is mostly poor)
Li et al (2015b)	CS (population-based)	India (SA, LM)	Both	250,752	Dementia-associated disability (screen + CE)	Income	Yes	People with dementia were not more likely to be above the national average income compared to below (OR=0.92, CI: 0.77-1.10)	Non-significant	–	Low
Lopes et al (2007)	CS (population-based)	Brazil (LAC, LM)	Urban	1,145	Cognitive and functional impairment (MMSE, FOME, IQCODE, B-ADL)	SES	Yes	Higher prevalence of CFI in lower SES, not significant after adjusting OR=4.00 (95% CI: 1.81–8.87), aOR=ns	Non-significant	–	Medium (low response rate)
Peres et al (2015)	CS (population-based)	Brazil (LAC, UM)	Urban	1,705	Severe cognitive impairment (MMSE)	Income	No	People with cognitive impairments were more likely to belong to the poorest compared to the highest quartile of household income (OR=4.9, 95%CI:2.7-8.8)	Positive	–	Medium (no adjusting)

Saha et al (2010)	CS (population-based)	India (SA, L)	Rural	179	Cognitive impairment (MMSE)	Income	Yes	Higher prevalence of cognitive impairment among people with lower income: OR=2.32 (95%CI: 1.18-2.32); aP-value: 0.05	Positive	–	Medium (small sample, reliability of disability measure)
Scazufca et al (2008)	CS (population-based)	Brazil (LAC, LM)	Urban	2005	Dementia (10/66 Dementia Research Group dementia diagnostic tool)	Income	Yes	Prevalence of dementia increased with decreasing income (p<0.001); Lowest to highest income group: aOR 3.38 (1.63-6.98) aP for trend <0.001	Positive	–	Low
Sengupta et al (2014)	CS (population-based)	India (SA, L)	Both	3,038	Cognitive impairment (modified Hindi Mental State Examination)	Income	Yes	People with cognitive impairment were more likely to have a monthly per capita household income of less than Rs 1000	Positive	Positive	Low
Singh et al (1999)	CS (population-based)	India (SA, L)	Urban	595	Cognitive deficits (Author-made questionnaire)	SES	No	Higher prevalence of cognitive deficits in poorer socio-economic classes (p<0.01)	Positive	–	Medium (no adjusting, response rate unclear)
Sosa et al (2012)	CS (population-based)	8 countries	Both	15,376	Mild cognitive impairment (NP battery)	Assets	Yes	Lower prevalence of mild cognitive impairment associated with ownership of more assets compared to less assets: aOR (pooled) = 0.88 (0.82-0.95)	Positive	–	Low

Study design abbreviations: CC=case control, CS=cross-sectional; Means of assessment abbreviations: AGE CAT= Automated Geriatric Examination for Computer Assisted Taxonomy, B-ADL: basic activities of daily living, CE=clinical evaluation, DDST=Denver Developmental Screening Test, GMS= Geriatric Mental State, IQCODE=Informant Questionnaire on Cognitive Decline in the Elderly, MMSE=mini-mental state evaluation, PFAQ=Pfeffer Functional Activities Questionnaire WGSS=Washington Group Short Set; Study location: EA=East Asia & Pacific, Eur=Europe & Central Asia, LAC=Latin America and the Caribbean, ME=Middle East & North Africa, SA=South Asia, SSA=Sub-Saharan Africa, L = low income country, LM=lower middle income country, UM=upper middle income country; Economic measure abbreviation: SES=socioeconomic status; Overview of results abbreviations: CI=confidence interval, OR=odds ratio, aOR=adjusted odds ratio, PR=prevalence ratio, aPR=adjusted prevalence ratio; \*study is repeated in more than one category (results have been disaggregated by disability type)



**Table 5: Summary of studies examining reported functional limitations, general disability**

Citation	Study design	Study location (region, income)	Rural/urban	Sample size	Disability measure	Economic measures	Adjusted	Overview of results	Summary of poverty and disability	Summary disability and work	Risk of bias (sources of bias)
<i>ALL AGES</i>											
Arokiasamy et al (2015)*	CS (population-based)	6 countries	Both	42,236	Difficulties in ADL (SAGE measures, based on WHODAS 2.0)	SES	No	SES negatively associated with having at least one limitation in ADL	Positive	–	Medium (no adjusting, response rate low, analysis unclear)
Danquah et al (2014)	CC (population-based)	Haiti (LAC, L)	Urban	254	Functional limitations (WGSS, “some difficulty” in 2+ activities or “a lot”/“cannot do” for 1+)	Assets	Yes	People with functional limitations were not more likely to belong to the lowest vs highest SES quartile (aOR: 1.3, 95% CI: 0.7-2.3)	Non-significant	Positive	Low
Ergin & Kunst (2015)	CS (population-based)	Turkey (Eur, LM)	Both	10,791	Functional limitations (WHS questions)	Assets	Yes	People with functional impairments were more likely to belong to the poorest wealth group compared to richest (various models, all p<0.05)	Positive	–	Low (disability measure picks up more severe forms)
Filmer (2008)	CS (population-based)	13 countries	Both	891,466	All disability (National household surveys, disability definition varies)	SES	Yes	Children: positive and significant in 2/14 surveys (India, Indonesia); Adults: positive, significant in 8/12 surveys	Positive	–	Medium (no response rates, disability measure varies, not always robust)
Hoogeveen (2005)	CS (population-based)	Uganda (SSA, L)	Both	447,498	General disability in head of household (Population and Housing Census 1991, disability: impairment preventing labour in past week)	PCE	Yes	Lower mean per capita expenditure among households with a disabled household head (significant difference in 3/4 regions); households with disabled head more likely to be below the poverty line (significant in 4/4 regions)	Positive	–	Low
Minh et al (2015)	CS (population-based)	Vietnam (EA, LM)	Both	4,224	Self-care, communication (WGSS, at least “some difficulty”)	Income	Yes	Households with members with remembering difficulty had “extra costs” of 10.5 (-5 to 26%) for self-care and 32.9% (17.6-48.2%) for communication	Positive	–	Low
Mont & Nguyen (2011)	CS (population-based)	Vietnam	Both	36,645	Functioning (WGSS, “some difficulty” in 2+ activities, “a lot of difficulty” or “cannot do” in 1+ activities)	PCE	Yes	Households with a person with a disability are over-represented in the lower consumption quartiles (various models, most p<0.01)	Positive	Positive	Low
Palmer et al (2012)	CS (population-based)	Vietnam (EA, L)	Both	60,737	Functional difficulties and ADL (questionnaire, ICF based)	Assets	No	People with disabilities were poorer than people without disabilities PR= 1.76 (severe: PR = 1.83); p<0.001	Positive	–	Medium (no adjusting)
Palmer et al (2014)	CS (population-based)	Vietnam (EA, L)	Both	390,070	Functional limitations (WGSS, “a lot” or “cannot do” to 1+ activity)	Income	Yes	People with disabilities were more likely to experience health care induced poverty	Positive	–	Medium (no adjusting)

								compared to other target insurance groups (p<0.001)			
Subbaraman et al (2014)*	CS (population-based)	India (SA, LM)	Urban	521	Functional limitations (WHODAS 2.0)	Income	Yes	People in the richest household income category were less likely to have functional limitations compared to those in the poorest (aOR: 0.31 (0.10-0.97))	Positive	–	Low
Trani et al (2015b)	CC (population-based)	Morocco, Tunisia (ME, LM)	Both	2,509	Activity limitations (Disability Screening Questionnaire)	SES Assets	Unclear	People with disabilities were multidimensionally poorer in both countries compared to people without disabilities (p<0.001), also poorer when just considering assets	Positive	Positive	Medium (methods unclear, including if adjusted for confounding)
<i>CHILDREN</i>											
Dang et al (2016)	CS (population-based)	Vietnam (EA, LM)	Both	1,314	Functional impairment (Brief Impairment Scale)	Income	Yes	Increased prevalence of functional impairment in children with decreasing household income (p<0.01)	Positive	–	Medium (no response rate; controlled for area, otherwise unclear)
Kawakatsu et al (2012)	CS (population-based)	Kenya (SSA, L)	Rural	339	Hearing, physical, visual, cognitive impairment and epilepsy (TQQ, CE, NP battery)	Income	Yes	Children with disabilities more likely to be in poorest income group compared to those without (OR=ns; aOR=2.79 (95%CI=1.28-6.08))	Positive	–	Medium (validity of economic measure, small sample, sampling strategy may lead to bias)
Kumar et al (2013)*	CS (population-based)	India	Both		Neurological disorders: epilepsy, global developmental delay, and motor, vision, and hearing)	Income assets	Yes	Both asset ownership and income were lower among families with child with a disability, but this difference was only significant for asset ownership (p<0.001)	Positive	–	Low
Kuper et al (2014)	CS (program participants)	30 countries	Both	898,834	Multiple types of impairments (parent-reported)	SES	Yes	9/30 countries showed a positive association, 15/30 no association and 6/30 a negative association	Mixed	–	Medium: limited adjustment, sampling may lead to bias
Kuper et al (2015)	CC (by key informants)	Kenya (SSA, L)	Rural	807	Moderate/severe impairments (UNICEF-Washington Group questionnaire, confirmed CE)	Assets	Yes	There was no significant difference in asset score between households with and without a child with a disability (aOR: 0.8, 95% CI: 0.5-1.2)	Non-significant		Low (not population-based, but sampling strategy validated)
Loyalka et al (2014)	CS (population-based)	China (EA, LM)	Both	2.5 million	Mixed impairment types (screened and CE confirmation)	Income	No	Income of households with a person with a disability on average 2,150 yuan (one person) to 3427 yuan (2+ people with disabilities) less and this was significant	Positive	–	Medium: no adjustment
Marella et al (2015)	CS (population-based)	Bangladesh (SA, L)	Both	1,855	Mixed impairment types (Rapid Assessment of Disability)	Assets	Yes	Compared to people in the highest wealth quintile, households in the bottom quintile were more likely to have a member with a disability (aOR=1.9, 95%CI: 1.09-3.3)	Positive	Positive	Low

Natale et al (1992)*	CS (population-based)	India	Urban	640	Serious disability (TQQ)	Income	Yes	Higher proportion of families with disabilities living in area with lowest family income compared to next lowest: aOR=2.39 (95% CI: 1.85-3.09)	Positive	–	Medium: validity of economic measure
Ou et al (2015)*	CC (school-based)	China (EA, UM)	Both	1,301	Mixed impairments (self-report of clinical diagnosis)	Income	Yes	There was a significant difference between households with and without a child with disabilities (p<0.001)	Positive	–	Medium (likely selection bias, controls not well matched on gender)
Pham et al (2013)*	CS (population-based)	Vietnam (EA, L)	Both	9,882	Self-care, communication (WGSS, at least “some difficulty”)	Income	No	People with communication difficulty more likely to belong to lower household income groups (p-trend: 0.001); no difference for people with self-care difficulty	Positive	–	Medium (no adjusting)
Trani et al (2013)	CS (population-based)	Afghanistan (SA, L)	Both	1,184	Mixed impairment types (questionnaire based on ICF)	SES Assets	Unclear	Children with disabilities more likely to belong to multidimensionally poorer households, as well as households with fewer assets	Positive		Low
<b>ADULTS</b>											
Hosseini et al (2013)	CS (population-based)	49 countries	Both	218,737	Functioning (World Health Survey)	SES	Yes	Disability prevalence highest in poorest compared to richest wealth quintiles. Unadjusted: all positive but significant for 16/18 (LICs), 14/15 (lower MICs), 9/9 (upper MICs) Adjusted: all positive but significant for 9/18 (LICs), 7/15 (lower MICs), 7/9 (upper MICs)	Positive	–	Low
Mitra et al (2013)	CS (population-based)	15 countries	Both	91,824	General disability - functional limitations (World Health Survey)	1. PCE 2. Assets	Yes	1. Higher proportion of households with disabilities under the extreme poverty line compared to households without disabilities, significant in 3/15 countries 2. Households with disability are more likely to be asset deprived in 12/15 countries but only statistically significant in 4/15 in countries	Positive	Positive	Low
Trani et al (2012)	CC (nested, population-based)	Afghanistan (SA, L), Zambia (SSA, L)	Both	5,032	General disability (questionnaire, ICF based and WGSS)	Assets	Yes	Asset ownership not significantly different between people with and without disabilities	Non-significant	Positive	Low
<b>OLDER ADULTS</b>											
Basu & King (2013)	CS (population-based)	India (SA, LM)	Both	7,150	Functional limitations (WHODASi 2.0)	Income	Yes	Wealth inversely associated with functional limitations (p<0.001)	Positive		Low
Beydoun et al (2005)	Cohort (population-based, 3 years)	China (EA, LM)	Both	976	Functional status decline: ADL (IADL, modified Katz questionnaire)	Income	Yes	Incidence of functional status decline increased with decreasing household income (adjusted for age/gender), but not significant after controlling for rural-urban residence and living arrangements).	Positive	–	Low (slightly high loss to follow-up, 26%)

Falkingham et al (2011)*	CS (population-based)	Kenya (SSA, L)	Urban	2,037	Self-reported functioning – self-care, interpersonal and life activities (WHODAS)	SES	Yes	Higher wealth status associated with reporting less disability (p<0.001)	Positive	Positive	Low
Fillenbaum et al (2010)	CS (population-based)	Brazil (LAC, UM)	Urban	6,958	Limitations in ADL -help needed with daily activities (self-reported)	Income	Yes	Individuals with incomes below US\$200 reported more limitations in ADL (OR significant in 5/5 categories; aOR significant for 3/5)	Positive	–	Medium (validity of disability measure)
Guerra et al (2008)	CS (population-based)	Brazil (LAC, UM)	Urban	2,143	Disability in ADL (questionnaire, self-reported)	Income	Yes	Perceived insufficient current income (aOR=1.91, 95% CI: 1.49-2.45) and poor childhood economic situation (aOR=1.29, 95% CI: 1.02-1.64) were both associated with higher prevalence of disability in ADL.	Positive	–	Medium (validity of economic and disability measures)
Gureje et al (2006)[6]	CS (population-based)	Nigeria (SSA, L)	Both	2,152	Disability in ADL and IADL (Katz index, Nagi scale)	Assets	Yes	No significant association between asset ownership and disability in ADL or IADL.	Non-significant	–	Medium (limited adjustment for confounders)
Liu et al (2009)	CS (population-based)	China (EA, LM)	Both	354,857	Functional disability, mobility focused (CE, using ICF criteria)	Income	Yes	Higher prevalence of disability in poorest compared to richest income group (OR=2.166, 95%CI: 2.075-2.262)	Positive	Positive	Low
Razzaque et al (2010)	CS (population-based)	Bangladesh (SA, L)	Rural	4,000	Functional ability (WHODASi)	SES	Yes	Poorer functional ability scores in lower SES groups	Positive	–	Low
Wandera et al (2014)	CS (population-base)	Uganda (SSA, L)	Both	2,382	Activity limitations (WGSS, “some difficulty” in 2+ activities, “a lot of difficulty” or “cannot do” in 1+ activities)	PCE	Yes	Household per capita consumption was not significantly associated with having a member with a disability.	Non-significant	–	Low
Williams et al (2015)	CS (population-based)	6 countries	Both	29,807	Functional limitations (WHODAS 2.0)	Assets	Yes	Prevalence of disability increased with decreasing wealth status (p<0.01)	Positive		Low
Xavier Gómez-Olivé (2010)	CS (population-based)	South Africa (SSA, UM)	Urban	4,085	Functional limitations (WHODAS)	Assets	Yes	Higher prevalence of disability in poorest compared to wealthiest group OR = 1.24 (95% CI: 1.03 - 1.50)	Positive	Positive	Medium (low response rate, particularly of men; exclusion of people with hearing impairment)

Study design abbreviations: CC=case control, CS=cross-sectional; Means of assessment abbreviations: ADL= activities of daily living, CE=clinical evaluation, IADL: instrumental activities of daily living, ICF: International Classification of Functioning, Disability and Health, NP:=neuropsychological, TQQ=Ten Questions Questionnaire, WHODAS=WHO Disability Assessment Schedule, WHODASi: WHODAS inverted; Economic measure abbreviation: PCE=per capita expenditures, SES=socioeconomic status; Overview of results abbreviations: CI=confidence interval, OR=odds ratio, aOR=adjusted odds ratio

**Table 6: Summary of studies examining mental disorders**

Citation	Study design	Study location	Rural/urban	Age group	Disability measure	Economic measure	Adjusted	Overview of results	Summary of poverty and disability	Summary disability and work	Risk of bias (source of bias)
<b>DEPRESSION &amp; ANXIETY</b>											
<i>ALL AGES</i>											
Arokiasamy et al (2015)*	CS (population-based)	6 countries	Both	42,236	Difficulties in ADL (SAGE measures, based on WHODAS 2.0)	SES	No	SES negatively associated with having depression	Positive	–	Medium (no adjusting, low response rate, analysis unclear)
Liu et al (2015a)	CS (population-based)	China (EA, UM)	Both	16,032	Major depressive disorder (SCID administered by clinician)	Income	Yes	People were more likely to have major depressive disorder if they were from lower income groups (p=0.002)	Positive	Positive	Low
Zhou et al (2015)	CS (population-based)	China (EA, UM)	Rural	11,473	Depression (PHQ-9)	Income	Yes	Lower income associated with depressive symptoms (p<0.001); aOR high to low income: 0.418, 95% CI: 0.32-0.54	Positive	–	Low
<i>CHILDREN</i>											
Wang et al (2015b)	CS (school-based)	China (EA, UM)	Rural	4,857	Depression (Children's Depression Inventory)	Income	Yes	Among children whose parents had migrated to urban centres, high household income was protective against depressive symptoms (aOR=1.56, 95% CI: 1.25-1.93 for lowest to highest income group).	Positive	–	Medium (school-based, sample not generalizable)
<i>ADULTS</i>											
Abas et al (1997)	CS (population-based)	Zimbabwe (SSA, L)	Urban	172	Depression and anxiety (Shona Screen for Mental Disorders, Present State Examination)	Income	Yes	Prevalence of depression/anxiety was higher in women with below average income compared to women with above average income (OR=2.22, 95% CI: 1.06-4.67); aOR=ns)	No significant association	–	Medium (small sample size, validity of economic measure)
Ball et al (2010)	CS (population-based)	Sri Lanka (SA, LM)	Both	5,968	Depression (CIDI)	SES	Yes	Lifetime prevalence of depression was higher in individuals from the poorest 2 quintiles of standard of living compared to those from the riches 3 quintiles (OR=1.33 (95%CI: 1.12–1.57), aOR=1.25 (95%CI 1.05–1.49)).	Positive	–	Low
Chen et al (2013)	CS (university students)	China (EA, LM)	Both	5,242	Depression (Beck Depression Inventory)	Income	Yes	Prevalence of depression higher among students from poor compared to good family economic situation (OR =1.80 95% CI: 1.51-2.15; aOR = 1.34 95% CI: 1.13-1.58)	Positive	–	Medium: school-based, potential selection bias

Hosseinpoor et al (2012)*	CS (population-based)	41 countries	Both	170,298	Depression (World Health Survey questionnaire, ICD-10)	SES	Yes	Lower SES correlated with higher prevalence of depression (Men: significant in 4/4 models; Women: significant in 3/4 models)	Positive	–	Low
Ibrahim et al (2012)	CS (university students)	Egypt (ME, L)	Both	1,366	Depression (Zagazig Depression scale - based on Hamilton Rating Scale)	Income	Yes	Lower prevalence of depression associated with higher income	Positive	–	Medium (specificity of disability measure, school-based)
Ma et al (2009)	CS (population-based)	China (EA, LM)	Both	5,926	General anxiety disorder, lifetime prevalence (CIDI, ICD-10)	Income	Yes	No association between income and general anxiety disorder	Non-significant	Non-significant	Low
Sozmen & Unal (2014)*	CS (population-based)	Turkey (ME, UM)	Both	14,433	Depression (self-report)	Income	Yes	Depression prevalence increased with decreasing wealth (relative index of inequality: 1.99 (1.44-2.75))	Positive	–	Low
Topuzoglu et al (2015)	CS (population-based)	Turkey (ME, UM)	Both	4,011	Clinical major depressive disorder (CIDI 2.1, sect E)	Income	Yes	Clinical depression increased with decreasing monthly income, but not significantly (high to low income: aOR=1.4 (0.9-2.2))	Non-significant	Positive	Low
Vukovic et al (2008)	CS (population-based)	Serbia (Eur, UM)	Both	14,552	Anxiety and depression (self-report)	SES	Yes	People with depression were more likely to belong to the lowest wealth quintile compared to the highest: aOR (men) = 2.98 (95% CI: 1.68-5.26); aOR (women) = 1.56 (95% CI: 1.06)	Positive	–	Medium (validity of disability measure)
Weobong et al (2014)	Cohort (population-based)	Ghana (SSA, L)	Both	21,135	Antenatal depression (PHQ-9)	Assets	Yes	Women who were poorer were more likely to have antenatal depression (p=0.015, aOR lowest to highest: 1.30, 95% CI: 1.09-1.55)	Positive	–	Low
Wu et al (2013)*	CS (population-based)	China (EA, UM)	Both	13,157	Depression (self-report)	SES	Yes	There was no difference in prevalence of depression between the lowest and highest quintile of SES	Non-significant	–	Medium (validity of disability measure)
Wu et al (2014)	CS (population-based)	China (EA, LM)	Urban	2,080	Anxiety, depression, PTSD (SRQ-20)	Income	Yes	People with lower incomes more likely to experience psychological symptoms (p<0.01)	Positive	–	Low
<b>OLDER ADULTS</b>											
Blay et al (2007)	CS (population-based)	Brazil (LAC, UM)	Both	6,961	Depression (Short Psychiatric Evaluation Schedule)	Income	Yes	Prevalence of depression was significantly higher in individuals with incomes below the poverty threshold compared to individuals at or above it OR=2.19 (95%CI: 1.97-2.43); aOR=1.53 (95% CI: 1.35-1.75).	Positive	Positive	Medium (sampling methods unclear)
Chen et al (2005)	CS (population-based)	China (EA, LM)	Rural	1,600	Depression (GMS-AGECAT)	Income	Yes	Prevalence of depression was higher in older adults from the lowest income group compared to highest (OR=8.14 (95% CI: 4.13-16.06); aOR=2.49 (95% CI: 1.17-5.28).	Positive	–	Medium (validity of economic measure)
Dasgupta et al (2013)	CS (population-based)	India (SA, LM)	Rural	85	Depression (Yesaverage's Geriatric Depression Scale, short form)	Income	Yes	Depression was more prevalent in those living below Rs 1000 compared to above (aOR=7.6, 95%CI: 1.9-31.8)	Positive	–	Medium (small sample size, response rate unclear)

Guerra et al (2009)	CS (population-based)	Peru, Mexico, Venezuela	Both	5886	Depression (DSM-IV and ICD-10 criteria, GMS-AGECAT, EURO-D, ICD-10 depressive episode)	Assets	Yes	No significant association with number of household assets for any country, before or after adjustment.	Non-significant	–	Medium (lack of information of study participants, analysis)
Guo et al (2014)	CS (population-based)	China (EA, LM)	Both	629	Depression (CES-D)	Income	No	People whose personal income was in the highest group were less likely to experience depression than those in the poorest group (aOR=0.4, 95%CI: 0.17-95)	Positive	–	Medium (no adjustment, sensitivity of economic measure)
Gureje et al (2007)	CS (population-based)	Nigeria (SSA, L)	Both	1,897	Lifetime major depressive disorder (CIDI, DSM-IV)	Assets	No	Lower prevalence of depression in poorer SES groups. Highest vs lowest OR for = 0.5 (95%CI: 0.3-0.8))	Negative	–	Medium (limited adjustment)
Hanandita et al (2014)	CS (population-based)	Indonesia (EA, LM)	Both	577,548	Depression (SRQ-20)	PCE	Yes	Likelihood of having depression increased with decreasing PCE (p<0.05)	Positive	Positive	Low
Kulkarni & Shinde (2015)	CS (population-based)	India (SA, LM)	Both	7,150	Moderate/severe depression (ICD-10)	SES	Yes	People from the poorest SES group were more likely to experience depression compared to the richest (aOR=2.6, 95%CI: 1.7-3.9)	Positive	–	Low
Fernandez-Nino et al (2015)	CS (population-based)	Mexico (LAC, UM)	Both	8,874	Clinically significant depressive symptoms (CES-D)	Assets	Yes	People from the lowest tertile of asset ownership were more likely to experience depressive symptoms compared to those in the highest (p<0.01)	Positive	Non-significant	Low
Lei et al (2014)	CS (population-based)	China (EA, UM)	Both	14,923	Depression (CES-D)	PCE	Yes	Increase in PCE associated with a decline in CES-D score (less depression) (p<0.05)	Positive	–	Low
Li et al (2011)	CS (population-based)	China (EA, LM)	Both	1,921	Depression (GDS-15, score >7)	Self-rated wealth	Yes	People with depression more likely to be in the poorest economic group (OR= 17.69 (95%CI: 9.28–33.75); aOR=8.319 (p<0.001))	Positive	Non-significant	Medium (economic measure unclear)
Malhotra et al (2010)	CS (population-based)	Sri Lanka (SA, LM)	Both	999	Depression, clinically significant (GDS-15, score: ≥6)	Income	Yes	Higher prevalence of depression in lower income group Unadjusted = p<0.05, Adjusted (model 1)=p<0.05; (model 2) = 0.89 (95% CI: 0.76–1.04)	Positive	–	Medium (economic measure, analysis unclear, limited adjusting)
Minicuci et al (2014)	CS (population-based)	Ghana (SSA, L)	Both	4,724	Depression (self-report of diagnosis)	SES	No	People with depression were more likely to below to the poorest compared to highest SES group (p<0.05)	Positive)	–	Medium (no adjusting, validity of disability measure)
Rajkumar et al (2009)	CS (population-based)	India (SA, LM)	Rural	1,000	Depression (BMS, WHODAS, CERAD, HAS-DSS, Neuropsychiatric Inventory)	Income	Yes	Higher prevalence of depression among people with lower family income OR=2.47 (95% CI: 1.65–3.68), aOR=1.78 (95% CI: 1.08-2.91)	Positive	–	Low
Sengupta & Benjamin (2015)	CS (population-based)	India (SA, LM)	Both	3,038	Depression (GDS-15)	Income	Yes	People with incomes below Rs 1000 were more likely to experience depression compared to people at or above this threshold (aOR=2.17, 95%CI: 1.56-7.5)	Positive	Non-significant	Low

COMMON MENTAL DISORDERS											
ALL AGES											
Jenkins et al (2015)	CS (population-based)	Kenya (SSA, L)	Rural	1,157	Common mental disorders (CIS-R)	Assets	Yes	People from the lowest wealth group were more likely to have a common mental disorder than if they were from the highest wealth group (aOR=2.5, 95% CI: 1.4-4.8)	Positive	Negative	Low
Subbaraman et al (2014)	CS (population-based)	India (SA, LM)	Urban	521	Common mental disorders (GHQ-12)	Income	Yes	There was no difference in prevalence of common mental disorders between income groups.	No significant association	–	Low
ADULTS											
Anselmi et al (2008)	Cohort (hospital-based)	Brazil	Urban		Common mental disorders (SRQ-20, minimum 8 symptoms)	Income	Yes	Prevalence of CMD higher for those whose family income at birth was in the lowest group compared to the highest group; prevalence of CMD was higher amongst individuals who were in the lowest tertile of family income throughout their life course compared to individuals who were consistently in the first and second tertiles.	Positive	–	Low (hospital-based birth cohort)
Coelho et al (2009)	CS (population-based)	Brazil (LAC, LM)	Urban	1,327	Common mental disorders (SRQ-20, min 6 symptoms for women, 8 for men)	SES	Yes	Higher prevalence of CMD among poorer SES groups (p for trend <0.001). OR for poorest compared to wealthiest: OR=3.79 (95%CI: 2.34-6.14); aOR=3.33 (2.01-5.52)	Positive	Positive	Low
Graham et al (2014)	CS (population-based)	Vietnam Philippines Indonesia (EA, LM)	Both	3,026	Common mental disorders (SRQ-20)	Assets	Yes	People in the highest asset group were less likely to have a common mental disorder than those who were in the poorest (p<0.05 in all countries)	Positive	–	Low
Lima et al (1996)	CS (population-based)	Brazil (LAC, UM)	Urban	1,277	Common mental disorders (SRQ-20)	Income	Yes	Prevalence of CMD was higher in individuals from the poorest compared to richest tertile of family income (aOR= 2.25 (95% CI: 2.15–2.35))	Positive	–	Low
Ludermir et al (2001)	CS (population-based)	Brazil (LAC, UM)	Rural	621	Common mental disorders (SRQ-20)	Income	Yes	Higher prevalence of CMD among poorer income group OR=3.88 (95%CI: 2.1-7.1); aOR=2.4 (95% CI: 1.0-5.6)	Positive	–	Low
Nguyen et al (2015)	CS (population-based)	Vietnam (EA, L)	Rural	211	Postpartum common mental disorders (SCID-I)	SES	Yes	Women in the lowest 25% of household had higher risk of CMD 1 year after birth (aOR=4.3, 95%CI: 1.2-15.3) compared to women in the highest 75% of households	Positive	–	Medium (sample size small)



Patel et al (2006)	Cohort (population-based, 1 year)	India (SA, L)	Both	2,166	Common mental disorders, incident (Revised Clinical Interview Schedule, Scale for Somatic Symptoms)	Income	Yes	Increasing incidence of CMD with decreasing income (aP-for-trend p=0.04)	Positive	–	Low
Quadros et al (2015)	Cohort (hospital-based)	Brazil (LAC, UM)	Urban	3,642	Common mental disorders (SRQ-20)	Income	No	Prevalence of CMD highest in those who were poor over the 3 time periods and lowest in those who were non-poor over all 3 (p<0.001)	Positive	–	Medium (hospital-based, 32% loss to follow-up, no adjusting)
Rocha et al (2010)	CS (population-based)	Brazil (LAC, UM)	Urban	3,597	Common mental disorders (SRQ-20, score: ≥7)	Income	Yes	Higher prevalence of CMD associated with lower income (PR=1.94 (95%CI: 1.62-2.32), aPR:1.89 (95% CI: 1.44-2.48))	Positive	–	Medium (no response rate, sensitivity of economic measure)
<b>OTHER MENTAL DISORDERS</b>											
<i>ALL AGES</i>											
Ataguba et al (2011)*	CS (population-based)	South Africa (SSA, UM)	Both	–	Emotional disabilities (self-reported)	SES	Yes	Prevalence of emotional disabilities was disproportionately concentrated among lower SES quintiles (p<0.05)	Positive	–	Low
Ayazi et al (2014)	CS (population-based)	South Sudan (SSA, L)	Rural	1,200	Anxiety disorders (general, PTSD, panic disorder, OCD, etc) (MINI)	SES	Yes	People with any anxiety disorders were more likely to belong to the lowest SES category (many models, e.g. Men: aOR=4.6, 95% CI: 2.1-10.4; women: aOR=3.5, 95%CI: 1.0-11.9)	Positive	–	Low
Gawde et al (2013)	CS (population-based)	India (SA, LM)	Urban	600	Psychiatric disorders (Symptoms Checklist 90)	Income	Yes	No significant difference in prevalence of psychiatric disorders between people from the highest two and lowest two income groups (aOR=1.0, 95%CI: 0.6-1.8)	Non-significant	Positive	Medium (insufficient power for analyses)
Husain et al (2014)	CS (population-based)	Pakistan (SA, LM)	Urban	880	Psychological distress (SRQ-20)	Income	Yes	Having a low income associated with higher SRQ score, significant in pooled (p=0.01) and for women only (p<0.001)	Positive	–	Low
Liu et al (2015b)	CS (population-based)	China (EA, LM)	Both	1.9 million	Schizophrenia (screening + CE)	Income	Yes	People from the lowest household income per capita group were more likely to experience schizophrenia compared to the highest (p<0.05)	Positive	–	Low
Trani et al (2015a)	CC (hospital – cases; population – controls)	India (SA, LM)	Urban	1,033	Schizophrenia, affective disorders (CE based on ICD-10)	Assets Income PCE	Unclear	People with severe mental illness had fewer assets (p<0.0001) and personal (p<0.0001)/household (p=0.002) income than controls. Not significant for PCE	Positive	Positive	Medium (lack/unclear adjusting)
Wang et al (2015a)	CS (population-based)	China (EA, UM)	Urban	16,866	Severe mental stress (Perceived Stress Scale)	Income	Yes	People from the highest income group were less likely to experience severe mental stress compared to people from the lowest income group (aOR=0.3, 95% CI: 0.2-0.4)	Positive	–	Low
<i>CHILDREN</i>											

Ali et al (2013)*	Cohort (population-based)	Pakistan (SA, L)	Urban	420	Emotional development (Early Child Development Tool, by Aga Khan University)	Income	Yes	No significant difference in emotional development between children from household's with father's income below or above 3500 rupees/month	Non-significant	–	Medium (low response rate, high loss to follow-up)
Anselmi et al (2012)	Cohort (hospital-based)	Brazil	Urban		Conduct, emotional or attention/hyperactivity problems (Strengths and Difficulties Questionnaire score, parent-reported)	Income	Yes	Prevalence of conduct, emotional and attentional/hyperactivity problems were higher in adolescents from families consistently in the lowest tertile of income compared to adolescents from the highest tertile.	Positive	–	Low (hospital-based birth cohort)
Escueta et al (2014)*	CC (population-based)	Mix (5 countries)	Both	1,780	Emotional difficulties (KABC-II)	Assets	Yes	Emotional difficulties score increased with increasing wealth ( $p < 0.01$ )	Positive	–	Low
Fortes et al (2016)	CS (school-based)	Brazil (LAC, UM)	Urban	1,338	DSM-5 learning disorders (Brazilian Academic Performance Test; exclusion of ID)	SES	Yes	Learning disorders were more prevalent in the two lowest SES groups compared to the two highest (aOR=2.8, 95% CI: 1.0-8.2)	Positive	–	Medium (school-based)
Petresco et al (2014)	Cohort (hospital-based)	Brazil (LAC, UM)	Urban	3,585	Psychiatric disorders	SES	No	Children born into lowest SES quintile were more likely to develop psychiatric disorders compared to children born in the highest SES quintile ( $p < 0.001$ )	Positive	–	Medium (no adjusting, unclear response rate)
Shams et al (2011)	CS (high school students)	Iran (ME, UM)	Rural	909	Obsessive compulsive disorder (Maudsley Obsessional-Compulsive Inventory and SCL-90-R)	Income	No	No significant association between level of income and prevalence of OCD, although OCD was more prevalent in the poorest income group compared to highest income group (OR= 2.78 (95% CI: 1.04-7.50))	Positive	–	Medium (no adjusting, response rate unclear, analysis unclear)
<b>ADULTS</b>											
Awas et al (1999)	CS (population-based)	Ethiopia (SSA, L)	Rural	501	Mental disorders (mood disorders, phobic disorders, other anxiety disorders, somatoform disorder) (CIDI)	Income	Yes	Prevalence of mental disorders was higher in the low income group compared to the medium and high income groups. This difference was only significant for mood disorders in low vs medium income groups.	Positive	–	Medium (validity of economic measure)
Blue (2000)	CS (population-based)	Brazil (LAC, UM)	Urban	1,739	Psychiatric morbidity (Questionnaire for Adult Psychiatric Morbidity)	Income	Yes	Prevalence of psychiatric disability was higher in adults from families in the lowest income group compared to those in the highest (OR=2.34 (95% CI: 1.71-3.20), aOR=1.49 (95%CI: 1.0-2.2)).	Positive	–	Low (no response rate)
Brown et al (2013)	Pre-post (population-based)	Vietnam (EA, L)	Both	798	Psychiatric symptoms (SRQ-20)	Assets	Yes	Psychiatric symptoms increased with decreasing asset ownership ( $p < 0.05$ )	Positive	–	Low

Islam et al (2003)	CS (population-based)	Bangladesh (SA, L)	Urban	149	Psychiatric disorders (SRQ, CE)	PCE	Yes	Prevalence of psychiatric disorders increased significantly with higher per capita expenditure (ap<0.001)	Negative	–	Low
Kawakami et al (2012)	CS (population-based)	11 countries	Both	37,741	Early onset (before individual completed education) mental disorders (CIDI, WMHS)	Income	Yes	Early onset mental disorders associated with low current household income significant in middle but not low income countries	Positive, mixed significance	Positive	Medium (reliability of economic measure, high non-response to income questions)
Levinson et al (2010)	CS (population-based)	9 countries	Both	21,104	Serious mental illness (CIDI, serious = score in “severe range” on Sheehan Disability Scales or attempting suicide)	Income	Yes	Proportion of respondents with low and low-average earnings significantly higher among those with compared to without serious mental illness (p<0.001). Respondents with serious mental illness earned 33% less than median earnings (p<0.05)	Positive	–	Medium (reliability of economic measure)
Li et al (2012)	CS (population-based)	China (EA, LM)	Both	1.8 million	Psychiatric disability (CE, ICD-10 for diagnosis, WHO-DAS11 severity)	Income	Yes	People with psychiatric depression more likely to be living below poverty line (aOR= 2.25(95% CI: 2.15–2.35)	Positive	–	Low (no response rate)
Li et al (2015a)	CS (population-based)	China (EA, LM)	Both	2.5 million	Mood disorder (WHO-ICF, CE)	Income	No	People living below the national average for family income per capita were more likely than those living at or above the average to have a mood disorder (p=0.001)	Positive	–	Medium (no adjusting)
Medina-Mora et al (2005)	CS (population-based)	Mexico (LAC, UM)	Urban	5,826	Psychiatric disorders, 12 month prevalence (CIDI, any DSM-IV disorder)	Income	Yes	People from low OR=2.7 (95% CI: 1.3-5.4) and low-average (aOR 2.0, 95% CI 1.0-4.0) incomes more likely to report severe disorder. No significant difference for other specific disorders (mood, anxiety, impulse-control or substance abuse)	Positive	–	Medium (unclear economic measure, slightly low response rate)
Mokhtari et al (2013)	CS (university students)	Iran (ME, UM)	Urban	1,572	Mental health problems (GHQ-28)	Income	No	Poorer GHQ scores among lower income groups (p<0.05)	Positive	–	Medium (no adjusting, school-based)
Myer et al (2008)	CS (population-based)	South Africa (SSA, LM)	Both	4,351	Psychological distress in past 30 days (K-10)	Income Assets SES	Yes	Prevalence of psychological distress significantly associated with SES (p<0.001). Prevalence higher among individuals in poorest income, asset and SES groupings compared to those in richest.	Positive	Positive	Low
Nguyen et al (2016)	CS (population-based)	India, Vietnam, Ethiopia	Both	5,647	Clinically significant maternal distress (SRQ-20)	SES	Yes	Mothers in the poorest SES group were more likely to have maternal distress compared to the highest SES group in Indian and Vietnam. There was no significant difference in Ethiopia.	Positive	Positive	Low
Norris et al (2003)	CS (population-based)	Mexico (LAC, UM)	Urban	2,509	Post-traumatic stress disorder (Module K of CIDI)	SES	Yes	Prevalence of PTSD increased with decreasing SES (p<0.001)	Positive	–	Low
Ou et al (2015)*	CC (school-based)	China (EA, UM)	Both	1,301	Autistic spectrum disorder (self-report)	Income	Yes	There was a significant difference between households with and without a child with autism (p<0.001)	Positive	–	Medium (likely selection bias,

					of diagnosis, CE using DSM-4)						controls not well matched on gender)
Santos et al (2014)	Cohort (clinic based)	Brazil (LAC, UM)	Urban	3,581	Antenatal and postnatal mood symptoms (SRQ-20)	Income	No	Higher prevalence of mood symptoms in women during pregnancy and postpartum from families with lower incomes (p trend <0.001)	Positive	–	Medium (not adjusted, hospital- based)
Sharifi et al (2015)	CS (population- based)	Iran (ME, UM)	Both	7,886	Psychiatric disorders (screen with CIDI 2, SCID-1 for CE)	Assets	Yes	People with higher SES have lower likelihood of having a psychiatric disorder (high to low: aOR=0.64 (0.52-0.78)	Positive	Positive	Low
Wang et al (2015d)	CS (population- based)	China (EA, LM)	Both	1.7 million	Mental disability (CE with ICD-10)	SES	Yes	Mental disability was significantly more prevalent among lower wealth groups (p trend<0.01; aOR highest to lowest: 0.15, 95%CI: 0.13-0.16)	Positive	–	Low
Xiang et al (2008)	CS (population- based)	China (EA, LM)	Urban	5,926	Schizophrenia (CIDI, ICD-10)	Income	Yes	Higher prevalence of schizophrenia among poorest group compared to wealthiest: OR = 14.29 (95% CI: 1.92-111.1); aOR = 19.23 (95% CI: 1.79-200)	Positive	Non- significant	Medium (lacks power, confidence intervals very broad)
<b>OLDER ADULTS</b>											
Soares et al (2015)	CS (population- based)	Brazil (LAC, UM)	Urban	1,125	Psychotic symptoms (Cambridge Mental Disorders of the Elderly Examination)	SES	Yes	People belonging to the lowest two social classes were more likely to experience psychotic symptoms compared to people in the top 3 classes (aOR=2.1, 95% CI: 1.2-3.7)	Positive	–	Medium (validity of disability measure, slightly low response rate)

Study design abbreviations: CC=case control, CS=cross-sectional; Means of assessment abbreviations: CE=clinical evaluation, CERAD=Clinical and Neuropsychology Assessment, CIDI=Composite International Diagnostic Interview, DSM: Diagnostic and Statistical Manual, GDS: Geriatric Depression Scale, GHQ-20: General Health Questionnaire, GMS-AGECAT: Geriatric Mental State-Automated Geriatric Examination for Computer Assisted Taxonomy, ICD: International Classification of Disease, MMSE: Mini Mental State Examination, SCL-90-R: Symptom Checklist-90-Revised, SRQ: Self-Reporting Questionnaire, WMHS: World Mental Health Survey, WHODAS: WHO Disability Assessment Schedule; Economic measure abbreviation: SES=socioeconomic status, PCE=per capita expenditures; Overview of results abbreviations: OR=odds ratio, aOR=adjusted odds ratio, CI=confidence interval; CMD=common mental disorders; \*study is repeated in more than one category (results have been disaggregated by disability type)

**S2 Table. Sample search string**

<i>Low and Middle Income Countries</i>	
1	developing countr*[MH] OR developing countr*[TIAB] OR developing nation*[TIAB] or developing world[TIAB]
2	least developed countr*[TIAB] OR least developed nation*[TIAB] OR least developed world[TIAB] OR least-developed countr*[TIAB] OR least-developed nation*[TIAB] OR less-developed countr* OR less-developed nation*[TIAB] OR less developed countr*[TIAB] OR less developed nation*[TIAB]
3	under-developed countr*[TIAB] OR under developed countr*[TIAB] OR underdeveloped countr*[TIAB] OR under-developed nation*[TIAB] OR under developed nation*[TIAB] OR underdeveloped nation*[TIAB] OR under-developed world[TIAB] OR under developed world[TIAB] OR underdeveloped world[TIAB] OR under-developed econom*[TIAB] OR under developed econom*[TIAB] OR underdeveloped econom*[TIAB]
4	third world countr*[TIAB] OR third world nation*[TIAB] OR third-world countr*[TIAB] OR third-world nation*[TIAB]
5	low- and middle-income countr*[TIAB] OR low and middle income countr*[TIAB] OR low- and middle-income nation*[TIAB] OR low and middle income nation*[TIAB] OR low- and middle-income world[TIAB] OR low and middle income world[TIAB] OR low- and middle-income econom*[TIAB] OR low and middle income econom*[TIAB] OR low income countr*[TIAB] OR middle income countr*[TIAB] OR low-income countr*[TIAB] OR middle-income countr*[TIAB] OR low income nation*[TIAB] OR middle income nation*[TIAB] OR low-income nation*[TIAB] OR middle-income nation*[TIAB] OR low income world[TIAB] OR middle income world[TIAB] OR low-income world[TIAB] OR middle-income world[TIAB] OR low income econom*[TIAB] OR middle income econom*[TIAB] OR low-income econom*[TIAB] OR middle-income econom*[TIAB]
6	LIC[TIAB] OR LICs[TIAB] OR MIC[TIAB] OR MICs[TIAB] OR LMIC[TIAB] OR LMICs[TIAB] OR LAMIC[TIAB] OR LAMICs[TIAB] OR LAMI countr*[TIAB]
7	Transitional countr*[TIAB] OR Transitional econom*[TIAB] OR Transition countr*[TIAB] OR Transition econom*[TIAB]
8	Asia[MH] OR Africa[MH] OR South America[MH] OR Caribbean region[MH] OR Central America[MH]
9	Afghanistan[TIAB] OR Albania[TIAB] OR Algeria[TIAB] OR American Samoa[TIAB] OR Angola[TIAB] OR Antigua[TIAB] OR Barbuda[TIAB] OR Argentina[TIAB] OR Armenia[TIAB] OR Azerbaijan[TIAB] OR Bangladesh[TIAB] OR Belarus[TIAB] OR Byelarus[TIAB] OR Byelorussia[TIAB] OR Belorussia[TIAB] OR Belize[TIAB] OR Benin[TIAB] OR Bhutan[TIAB] OR Bolivia[TIAB] OR Bosnia[TIAB] OR Herzegovina[TIAB] OR Hercegovina[TIAB] OR Bosnia-Herzegovina[TIAB] OR Bosnia-Hercegovina[TIAB] OR Botswana[TIAB] OR Brazil[TIAB] OR Brasil[TIAB] OR Bulgaria[TIAB] OR Burkina[TIAB] OR Upper Volta[TIAB] OR Burundi[TIAB] OR Urundi[TIAB] OR Cambodia[TIAB] OR Republic of Kampuchea[TIAB] OR Cameroon[TIAB] OR Cameroons[TIAB] OR Cape Verde[TIAB] OR Central African Republic[TIAB] OR Chad[TIAB] OR Chile[TIAB] OR China[TIAB] OR Colombia[TIAB] OR Comoros[TIAB] OR Comoro Islands[TIAB] OR Comores[TIAB] OR Congo[TIAB] OR DRC[TIAB] OR Zaire[TIAB] OR Costa Rica[TIAB] OR Cote

	d'Ivoire[TIAB] OR Ivory Coast[TIAB] OR Cuba[TIAB] OR Djibouti[TIAB] OR Obock[TIAB] OR French Somaliland[TIAB] OR Dominica[TIAB] OR Dominican Republic[TIAB] OR Ecuador[TIAB] OR Egypt[TIAB] OR United Arab Republic[TIAB] OR El Salvador[TIAB] OR Eritrea[TIAB] OR Ethiopia[TIAB] OR Fiji[TIAB] OR Gabon[TIAB] OR Gabonese Republic[TIAB] OR Gambia[TIAB] OR Georgia[TIAB] OR Ghana[TIAB] OR Gold Coast[TIAB] OR Grenada[TIAB] OR Guatemala[TIAB] OR Guinea[TIAB] OR Guinea-Bissau[TIAB] OR Guiana[TIAB] OR Guyana[TIAB] OR Haiti[TIAB] OR Honduras[TIAB] OR India[TIAB] OR Indonesia[TIAB] OR Iran[TIAB] OR Iraq[TIAB] OR Jamaica[TIAB] OR Jordan[TIAB] OR Kazakhstan[TIAB] OR Kenya[TIAB] OR Kiribati[TIAB] OR Republic of Korea[TIAB] OR North Korea[TIAB] OR DPRK[TIAB] OR Kosovo[TIAB] OR Kyrgyzstan[TIAB] OR Kirghizstan[TIAB] OR Kirgizstan[TIAB] OR Kirghizia[TIAB] OR Kirgizia[TIAB] OR Kyrgyz[TIAB] OR Kirghiz[TIAB] OR Kyrgyz Republic[TIAB] OR Lao[TIAB] OR Laos[TIAB] OR Latvia[TIAB] OR Lebanon[TIAB] OR Lesotho[TIAB] OR Basutoland[TIAB] OR Liberia[TIAB] OR Libya[TIAB] OR Lithuania[TIAB] OR Macedonia[TIAB] OR Madagascar[TIAB] OR Malagasy Republic[TIAB] OR Malawi[TIAB] OR Nyasaland[TIAB] OR Malaysia[TIAB] OR Malaya[TIAB] OR Malay[TIAB] OR Maldives[TIAB] OR Mali[TIAB] OR Marshall Islands[TIAB] OR Mauritania[TIAB] OR Mauritius[TIAB] OR Mayotte[TIAB] OR Mexico[TIAB] OR Micronesia[TIAB] OR Moldova[TIAB] OR Moldovia[TIAB] OR Mongolia[TIAB] OR Montenegro[TIAB] OR Morocco[TIAB] OR Mozambique[TIAB] OR Myanmar[TIAB] OR Burma[TIAB] OR Namibia[TIAB] OR Nepal[TIAB] OR Nicaragua[TIAB] OR Niger[TIAB] OR Nigeria[TIAB] OR Pakistan[TIAB] OR Palau[TIAB] OR Palestine[TIAB] OR Panama[TIAB] OR Papua New Guinea[TIAB] OR Paraguay[TIAB] OR Peru[TIAB] OR Philippines[TIAB] OR Romania[TIAB] OR Rumania[TIAB] OR Roumania[TIAB] OR Russia[TIAB] OR Russian Federation[TIAB] OR USSR[TIAB] OR Soviet Union[TIAB] OR Union of Soviet Socialist Republics[TIAB] OR Rwanda[TIAB] OR Ruanda-Urundi[TIAB] OR Samoa[TIAB] OR Samoan Islands[TIAB] OR Sao Tome[TIAB] OR Principe[TIAB] OR Senegal[TIAB] OR Serbia[TIAB] OR Montenegro[TIAB] OR Yugoslavia[TIAB] OR Seychelles[TIAB] OR Sierra Leone[TIAB] OR Solomon Islands[TIAB] OR Somalia[TIAB] OR South Africa[TIAB] OR Sri Lanka[TIAB] OR Ceylon[TIAB] OR Saint Kitts[TIAB] OR St Kitts[TIAB] OR Saint Christopher Island[TIAB] OR Nevis[TIAB] OR Saint Lucia[TIAB] OR St Lucia[TIAB] OR Saint Vincent[TIAB] OR St Vincent[TIAB] OR Grenadines[TIAB] OR Sudan[TIAB] OR Suriname[TIAB] OR Surinam[TIAB] OR Swaziland[TIAB] OR Syria[TIAB] OR Syrian Arab Republic[TIAB] OR Tajikistan[TIAB] OR Tadjikistan[TIAB] OR Tadjikistan[TIAB] OR Tanzania[TIAB] OR Thailand[TIAB] OR Timor-Leste[TIAB] OR East Timor[TIAB] OR Togo[TIAB] OR Togolese Republic[TIAB] OR Tonga[TIAB] OR Tunisia[TIAB] OR Turkey[TIAB] OR Turkmenistan[TIAB] OR Turkmenia[TIAB] OR Tuvalu[TIAB] OR Uganda[TIAB] OR Ukraine[TIAB] OR Uruguay[TIAB] OR Uzbekistan[TIAB] OR Vanuatu[TIAB] OR New Hebrides[TIAB] OR Venezuela[TIAB] OR Vietnam[TIAB] OR Viet Nam[TIAB] OR West Bank[TIAB] OR Gaza[TIAB] OR Yemen[TIAB] OR Zambia[TIAB] OR Zimbabwe[TIAB] OR Rhodesia[TIAB]
10	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9
11	Poverty[MH] OR poverty areas[MH]

12	Poverty[TIAB] OR economically disadvan*[TIAB] OR economic disadvan*[TIAB]
13	Income [TIAB] NOT income countr*[TIAB] NOT income setting*[TIAB] NOT income econom* NOT income nation*
14	Income [MH] OR earning*[TIAB] OR wage*[TIAB] OR salar*[TIAB] OR asset*[TIAB] OR expenditure per capita[TIAB] OR expenditures per capita[TIAB] OR personal expenditure*[TIAB] OR household expenditure*[TIAB] OR consumption per capita[TIAB] OR household consumption[TIAB] OR expenditure*[TIAB] OR financial status*[TIAB] OR wealth*[TIAB] OR socioeconomic status[TIAB] OR socio-economic status[TIAB] OR social class[MH] OR social class*[TIAB] OR social rank*[TIAB]
15	11 OR 12 OR 13 OR 14
16	Disabled person[MH] OR disabled person*[TIAB] OR person with disabilit* [TIAB] OR persons with disabilit*[TIAB] OR people with disability*[TIAB] OR handicapped person*[TIAB] OR handicapped people[TIAB]
17	Physical impair*[TIAB] or physically impair*[TIAB] OR physical deficien*[TIAB] OR physically deficien*[TIAB] OR physical disab*[TIAB] OR physically disab*[TIAB] OR physical handicap*[TIAB] OR physically handicap*[TIAB] OR physically challeng*[TIAB]
18	Cerebral palsy[MH] OR Cerebral pals*[TIAB] OR spinal dysraphism[MH] OR Spina bifida[TIAB] OR muscular dystrophies[MH] OR Muscular dystroph*[TIAB] OR Arthritis[MH] OR Arthrit*[TIAB] OR Osteogenesis imperfecta[TIAB] OR Musculoskeletal Abnormalities[MH] OR Musculoskeletal abnormalit*[TIAB] OR Musculo-skeletal abnormalit*[TIAB] OR Muscular abnormalit*[TIAB] OR Skeletal abnormalit*[TIAB] OR limb abnormalit*[TIAB] OR Chronic Brain Injury[MH]OR Amputation*[TIAB] or Amputee[TIAB] OR Clubfoot[TIAB] OR Poliomyelitis[MH] OR Polio*[TIAB] OR Paraplegia[MH] OR Paraplegi*[TIAB] OR Paralys*[TIAB] OR Paralyz*[TIAB] OR Hemiplegia[MH] OR Hemiplegi*[TIAB]
19	Hearing loss[MH] OR Hearing loss*[TIAB] OR hearing impair*[TIAB] OR hearing deficien*[TIAB] OR hearing disable*[TIAB] OR hearing disabili*[TIAB] OR hearing handicap*[TIAB] OR acoustic loss*[TIAB] OR acoustic impair*[TIAB] OR acoustic deficien*[TIAB] OR acoustic disable*[TIAB] OR acoustic disabili*[TIAB] OR acoustic handicap*[TIAB] OR Deaf*[TIAB] or hearing loss[TIAB]
20	Blindness[MH] OR vision loss*[TIAB] OR vision impair*[TIAB] OR vision deficien*[TIAB] OR vision disable*[TIAB] OR vision disabili*[TIAB] OR vision handicap*[TIAB] OR visual loss*[TIAB] OR visual impair*[TIAB] OR visually impair*[TIAB] OR visual deficien*[TIAB] OR visually deficien*[TIAB] OR visual disable*[TIAB] OR visually disable*[TIAB] OR visual disabili*[TIAB] OR visually disabili*[TIAB] OR visual handicap*[TIAB] OR visually handicap*[TIAB] OR low vision[TIAB] OR reduced vision[TIAB] OR (blind*[TIAB] NOT double blind*[TIAB] NOT blinding[TIAB] NOT triple blind*[TIAB])

21	Mental disorder*[TIAB] OR Schizophreni*[TIAB] OR Psychosis[TIAB] OR psychoses[TIAB] OR Psychotic Disorder*[TIAB] OR Schizoaffective Disorder*[TIAB] OR Schizophreniform Disorder*[TIAB] OR schizophrenia and disorders with psychotic features[MH] OR Dementia*[TIAB] OR Alzheimer*[TIAB]
22	intellectual illness*[TIAB] OR intellectual impair*[TIAB] OR intellectual deficient*[TIAB] OR intellectual disable*[TIAB] OR intellectual disabili*[TIAB] OR intellectual handicap*[TIAB] OR intellectual retard*[TIAB] OR mental ill[TIAB] OR mentally ill[TIAB]OR mental illness*[TIAB] OR mental impair*[TIAB] OR mentally impair*[TIAB] OR mental deficient*[TIAB] OR mentally deficient*[TIAB] OR mental disable*[TIAB] OR mentally disable*[TIAB] OR mental disabili*[TIAB] OR mental handicap*[TIAB] OR mentally handicap*[TIAB] OR developmental impair*[TIAB] OR developmentally impair*[TIAB] OR developmental deficient*[TIAB] OR developmentally deficient*[TIAB] OR developmental disable*[TIAB] OR developmentally disable*[TIAB] OR developmental disabili*[TIAB] OR developmentally disabili*[TIAB] OR developmental handicap*[TIAB] OR developmentally handicap*[TIAB] OR developmental retard*[TIAB] OR developmentally retard*[TIAB] OR psychological ill[TIAB] OR psychologically ill[TIAB] OR psychological illness*[TIAB] OR psychological impair*[TIAB] OR psychologically impair*[TIAB] OR psychological deficient*[TIAB] OR psychologically deficient*[TIAB] OR psychological disable*[TIAB] OR psychologically disable*[TIAB] OR psychological disabili*[TIAB] OR psychological handicap*[TIAB] OR psychologically handicap*[TIAB]
23	Learning disorders[MH] OR learning disorder*[TIAB] OR communication disorders[MH] OR communication disorder*[TIAB] OR language disorder*[TIAB] OR speech disorder*[TIAB] OR speech disorder*[TIAB]
24	Pervasive Child Development Disorders[MH] OR autistic[TIAB] OR autism[TIAB] OR asperger*[TIAB] or dyslexi*[TIAB] OR Down's Syndrome[TIAB] OR Down Syndrome[TIAB] OR Mongolism[TIAB] or Trisomy 21[TIAB]
25	16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24
26	10 AND 15 AND 25
27	Limit 26 to English language, publication type=case reports, comparative study, evaluation studies, government publications, journal article, meta-analysis, review, systematic reviews



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## Appendix 7: Web appendices to Paper 2

### Search Terms

#### Web of Science

(Disabl\* or Disabilit\* or Handicap\*)

AND

("Social security" OR "public assistance" OR "disability insurance" OR (disab\* NEAR/3 insurance) OR "social protection" OR "social securit\*" OR (safety NEAR/3 net\*) OR (cash NEAR/3 transfer\*) OR pension\* OR "social assistance" OR "Social insurance" or (micro NEAR/3 insurance) OR (disabilit\* NEAR/3 grant\*) OR (disabilit\* NEAR/3 benefit\*) OR "social pension\*" OR "universal pension\*" or (social NEAR/2 health NEAR/2 protection\*) OR "invalidity benefit\*" OR "income maintenance" OR (work NEAR/2 injur\*) OR (employment NEAR/2 injur\*) or "health insurance")

AND

("least developed countr\*" OR "least developed nation\*" OR "least developed world" OR "least-developed countr\*" OR "least-developed nation\*" OR "less-developed countr\*" OR "less-developed nation\*" OR "less developed countr\*" OR "less developed nation\*" OR "developing countr\*" OR "developing nation\*" OR "developing world" OR " under-developed countr\*" OR "under developed countr\*" OR "underdeveloped countr\*" OR "under-developed nation\*" OR "under developed nation\*" OR "underdeveloped nation\*" OR "under-developed world" OR "under developed world" OR "underdeveloped world" OR "under-developed econom\*" OR "under developed econom\*" OR "underdeveloped econom\*" OR "third world countr\*" OR "third world nation\*" OR "third-world countr\*" OR "third-world nation\*" OR "low- and middle-income countr\*" OR "low and middle income countr\*" OR "low- and middle-income nation\*" OR "low and middle income nation\*" OR "low- and middle-income world" OR "low and middle income world" OR "low- and middle-income econom\*" OR "low and middle income econom\*" OR "low income countr\*" OR "middle income countr\*" OR "low-income countr\*" OR "middle-income countr\*" OR "low income nation\*" OR "middle income nation\*" OR "low-income nation\*" OR "middle-income nation\*" OR "low income world" OR "middle income world" OR "low-income world" OR "middle-income world" OR "low income econom\*" OR "middle income econom\*" OR "low-income econom\*" OR "middle-income econom\*") OR

((LIC or LICs or MIC or MICs or LMIC or LMICs or LAMIC or LAMICs or "LAMI countr\*" or "third world")) OR ((("Transitional countr\*" or "Transitional econom\*" or "Transition countr\*" or "Transition econom\*")) OR ((Africa or Asia or Caribbean or "West Indies" or "Latin America" or "Central America" or "South America")))

## **EconLit**

(Disabl\* or Disabilit\* or Handicap\*).sh,ti,ab

AND

("Social security" OR "public assistance" OR "disability insurance" OR (disab\* ADJ3 insurance) OR "social protection" OR "social securit\*" OR (safety ADJ3 net\*) OR (cash ADJ3 transfer\*) OR pension\* OR "social assistance" OR "Social insurance" or (micro ADJ3 insurance) OR (disabilit\* ADJ3 grant\*) OR (disabilit\* adj3 benefit\*) or "social pension\*" or "universal pension\*" or (social adj2 health adj2 protection\*) or "invalidity benefit\*" or "income maintenance" or (work adj2 injur\*) or (employment adj2 injur\*) or "health insurance").sh,ti,ab

AND

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## **ERIC, ProQuest databases**

(Disabl\* or Disabilit\* or Handicap\*)

AND

("Social security" OR "public assistance" OR "disability insurance" OR (disab\* N/3 insurance) OR "social protection" OR "social securit\*" OR (safety N/3 net\*) OR (cash N/3 transfer\*) OR pension\* OR "social assistance" OR "Social insurance" or (micro N/3 insurance) OR (disabilit\* N/3 grant\*) OR (disabilit\* N/3 benefit\*) OR "social pension\*" OR "universal pension\*" or (social N/2 health N/2 protection\*) OR "invalidity benefit\*" OR "income maintenance" OR (work N/2 injur\*) OR (employment N/2 injur\*) or "health insurance")

AND

("least developed countr\*" OR "least developed nation\*" OR "least developed world" OR "least-developed countr\*" OR "least-developed nation\*" OR "less-developed countr\*" OR "less-developed nation\*" OR "less developed countr\*" OR "less developed nation\*" OR "developing countr\*" OR "developing nation\*" OR "developing world" OR " under-developed countr\*" OR "under developed countr\*" OR "underdeveloped countr\*" OR "under-developed nation\*" OR "under developed nation\*" OR "underdeveloped nation\*" OR "under-developed world" OR "under developed world" OR "underdeveloped world" OR "under-developed econom\*" OR "under developed econom\*" OR "underdeveloped econom\*" OR "third world countr\*" OR "third world nation\*" OR "third-world countr\*" OR "third-world nation\*" OR "low-and middle-income countr\*" OR "low and middle income countr\*" OR "low- and middle-income nation\*" OR "low and middle income nation\*" OR "low- and middle-income world" OR "low and middle income world" OR "low- and middle-income econom\*" OR "low and middle income econom\*" OR "low income countr\*" OR "middle income countr\*" OR "low-income countr\*" OR "middle-income countr\*" OR "low income nation\*" OR "middle income nation\*" OR "low-income nation\*" OR "middle-income nation\*" OR "low income world" OR "middle income world" OR "low-

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## Assessment Criteria by Study Design

### Quantitative studies

- 1. Sampling methods
  - Was the sample representative of the broader population?
  - Was recruitment of participants appropriate to the study question?
  - Adequate sample size (>100 or sample size calculation undertaken)
  - Response rate reported and acceptable (≥70%)
  - Control group is appropriate, clearly defined (if applicable)
- 2. Data collection
  - Sample characteristics clearly described
  - Means of collecting data (e.g. assessment tool, questionnaire, etc) valid, reliable
- 3. Data analysis/interpretation
  - Potential confounders taken into account during the analysis and interpretation
  - Tests for statistical significance undertaken, presented systematically

### Qualitative studies (adapted from RATS)

- 1. Study design
  - Study design is appropriate to the research question
    - Could a quantitative approach have worked better?
    - Justified why a particular method was chosen, e.g.:
      - Interviews: experience, perceptions, behaviour, practice
      - Focus groups: group dynamics, convenience, non-sensitive topics
      - Ethnography: culture, organisational behaviour, interaction
- 2. Sampling methods
  - Criteria for selecting study sample is appropriate
    - E.g. purposive (diversity of opinion), random (generalisable to broader population), volunteer (hard to reach groups)
  - Details given of how recruitment was conducted and by whom
  - Details given on who chose not to participate and why
- 3. Data collection
  - Collection of data is comprehensive and appropriate

- Was the study setting appropriate? E.g. protection of confidentiality for sensitive discussions
  - Is the role of the researcher(s) appropriate? How might they bias the study and results? e.g. Do researchers occupy dual roles (clinician and researcher)?
- 4. Data analysis/interpretation
  - Are interpretations clearly presented and supported adequately by evidence?
    - Indicators of quality:
      - Description of how themes were derived from the data (inductive or deductive)
      - Semi-quantification when appropriate
      - Quote use appropriate, effective
      - Analysis/presentation of negative/deviant cases, alternative explanations
      - Method of reliability check (e.g. triangulation, independent review of data to contest themes)
  - Are findings generalisable to a broader population?

#### Rubric

Low	All or almost of the above criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study.
Medium	Some of the above criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study.
High	Few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion.



**Supplemental Table 1. Risk of bias in the included studies**

<i><b>Citation</b></i>	<i><b>Overall risk of bias</b></i>	<i><b>Main sources of potential bias</b></i>
Berry & Smit (2011)	High	Findings not generalizable or statistically valid due to small sample size (n=18) recruited through convenience sampling; assessment tools not validated in local context.
Goldblatt (2009)	High	Lack of information on methodology for data collection, analysis and interpretation.
Graham et al (2012)	High	No information on sample characteristics; no statistical analysis or control for confounding; lack of information on sampling methods.
Jelsma et al (2008)	Medium	Potential selection bias, lack of control from confounding.
Levine et al (2011)	Low	Potential low reliability of some questions in data collection instrument.
Li et al (2013)	Medium	Lack of methodology on data analysis.
Loyalka et al (2014)	Medium	Sources of data may not be directly comparable; no tests for statistical significance undertaken.
Macgregor (2006)	High	Limited generalizability (observations from 1 clinic); lack of information on methodology; potential bias from researcher/clinician dual role.
Mitra (2008)	Medium	Issues around compatibility of two data sources; potential ecological fallacy.
Mitra (2010)	Low	Slight reliability issues of some questions in data collection instrument; secondary data analysis with sampling strategy not defined.
Palmer & Nguyen (2012)	Low	Potential issues in compatibility of two data sources.
Palmer et al (2012)	Low	n/a
Palmer (2014)	Low	n/a
Saloojee et al (2007)	Medium	Predominantly descriptive analysis with limited statistical inference; use of snowball sampling limits generalizability.
Vazquez et al (2011)	Medium	Potential selection bias; method of recruitment unclear.

## Appendix 8: Web appendices to Paper 3

### Supplementary File 1: Models for estimating extra costs of disability

A standard of living index was created through principal component analysis using a range of household assets and housing characteristics. Variables were selected after testing their relationship with income (included if statistically significant at the 5% level).

3 models were tested in each setting

- Model 1: OLS of standard of living index scores
- Model 2: Ordered logit of quintiles of standard of living index
- Model 3: Ordered logit, total number of assets (count)

### VIETNAM

	Model 1	Model 2	Model 3
Disability ( $\beta$ )	-0.59 (-0.86, -0.32)	-0.59 (-0.92, -0.25)	-0.61 (-0.92, -0.29)
Log income ( $\alpha$ )	0.54 (0.45, 0.63)	0.79 (0.63, 0.95)	0.71 (0.57, 0.86)
Extra costs (% household income)	109.3% (50.8-191.1%)	74.7% (26.3-146.0%)	85.9% (33.7-161.4%)

*Variables in standard of living index:* radio, TV, refrigerator, cupboard, car, motorbike, washing machine, air conditioner, electric cooker, internet access, computer, household ownership, number of members per sleeping room.

*X variables:* at least one member has a college education, ward, female headed, number of household members, proportion of dependents (children <16 and adults 65+ over household size)

## NEPAL

	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>
Disability ( $\beta$ )	-0.28 (-0.41, -0.05)	-0.28 (-0.52, -0.03)	-0.17 (-0.41, 0.06)
Log income ( $\alpha$ )	0.95 (0.85, 1.05)	0.96 (0.84, 1.07)	0.83 (0.72, 0.94)
Extra costs (%)	29.5% (4.8-48.2%)	29.2% (2.8-61.9%)	20.5% (-6.4-56.9%)

*Variables in standard of living index:* electricity, improved toilet, water source, material of wall, material of floor, material of roof, radio, TV, refrigerator, phone, cupboard, sofa, table, car, motorbike, sewing machine, bicycle, cooker with gas, electric cooker, internet, computer.

*X variables:* household size, location (urban/rural), number of children (<16), number of older adults (65+)

**Supplementary Table 1. MPI Indicators**

<i>Indicator</i>	<i>Threshold: Deprived if...</i>	<i>Definition</i>
Work & education	Individual (age 15-64) has not worked in the last 12 months and is not currently attending school; OR Individual (65+) is not working and does not receive a pension/age-based cash transfer	<b>All:</b> Individual reports not working (excluding domestic work) at any time during the last 12 months and is not a student. For individuals 65+, not receiving an Old Age Allowance or a pension.
Food security	Household faces food insecurity	<b>Nepal:</b> Assessed through USAID's Household Food Insecurity Access Scale <sup>1,2</sup> <b>Vietnam:</b> Household reports not having food to eat of any kind because of lack of resources in the last month
Voting	Individual did not vote in the last election, if eligible	<b>Nepal:</b> Did not vote and is aged 21+ (voting age is 18 and last election was 2013, 3 years before data collection). If age is 20 or under, counted as non-deprived. <b>Vietnam:</b> Did not vote and is above age 18 (voting age is 18 and last election right before data collection). If age is 17 or under, counted as non-deprived.
Decision-making	Individual not consulted in family decision-making	<b>All same question</b> Individual reports never being consulted in making family decisions. Question from SINTEF participation question set <sup>3</sup>
Sanitation	Individual faces difficulties accessing improved sanitation facility	<b>Nepal:</b> Deprived if: <ul style="list-style-type: none"> <li>- Household sanitation facility is unimproved (does not have flush toilet, ventilated pit latrine, pit latrine with slab or composting toilet) or is shared with other household (definition from UNDP MPI<sup>4</sup> and Nepal DHS 2011<sup>2</sup>); OR</li> <li>- Individual reports they cannot use the same facility as other adults in the household, require help to use the facility or come into contact with faeces or urine while using the facility.</li> </ul> <b>Vietnam:</b> Deprived if: <ul style="list-style-type: none"> <li>- Household does not have a non-shared flush toilet, OR</li> <li>- Individual reports that they have not had difficulty accessing toilet facility in the last 6 months.</li> </ul>
Water	Individual faces difficulties accessing safe drinking water	<b>Nepal:</b> Deprived if: <ul style="list-style-type: none"> <li>- Household water facility is not one of the following: connection (piped), public standpipe, tubewell or borehole, protected well or spring, rainwater collection, or bottled water (definition</li> </ul>

		<p>from UNDP MPI<sup>4</sup> Nepal DHS 2011<sup>2</sup>); OR</p> <ul style="list-style-type: none"> <li>- Individual does not use same water source as others in the household or cannot access stored water independently.</li> </ul> <p><b>Vietnam:</b> Deprived if:</p> <ul style="list-style-type: none"> <li>- Household does not have non-shared, piped water connection.</li> <li>- Individual reports that they have had difficulty accessing safe water to drink in the last 6 months.</li> </ul>
Healthcare	Household spent more than 25% of income on healthcare in the last month	<b>Nepal/Vietnam:</b> total spending on healthcare in the last month [sum of itemized expenditures]/average monthly income. Indicator comes from the World Health Organization's monitoring of the SDGs for financial protection. <sup>5</sup>
Health event	Individual experienced a serious health problem in the last 12 months	<b>All:</b> individual reports having a serious health event in the last 12 months.
Violence	Individual experienced discrimination, physical or verbal abuse in the last 12 months	<b>All:</b> Individual reports being beaten, scolded or discriminated against by any household member, relatives or at school or work. Questions derived from SINTEF Living Conditions Surveys. <sup>3</sup>
Cooking fuel	Household cooks with dung, wood or charcoal	<b>All:</b> self-reported main fuel used for cooking. These sources are defined as unclean cooking fuels linked to indoor air pollution, from the UNDP's MPI. <sup>4</sup>
Flooring	Household has dirt, sand or dung floor	<b>All:</b> assessed through interviewer observation of the flooring material. Defined as unfinished flooring in the UNDP's MPI. <sup>4</sup>
Overcrowding	Household is overcrowded (3+ people per sleeping room)	<b>All:</b> number of household members over number of rooms for sleeping is 3 or more. Definition from DHS Methodological Report 9. <sup>6</sup>
Assets	Household does not own more than one asset (among radio, TV, telephone, bike, motorbike, refrigerator, air conditioner, computer) and does not own a car	<b>All:</b> assessed through self-reported asset ownership. Definition of asset deprived from the UNDP's MPI <sup>4</sup>

<sup>1</sup> Coates, J., A. Swindale, and P. Bllinsky, *Household Food Insecurity Access Scale (HFIAS) for Measurement of Food Access: Indicator Guide* 2007, USAID: Washington, D.C.; <sup>2</sup> Ministry of Health and Population [Nepal], New ERA, and ICF International Inc, *Nepal Demographic and Health Survey 2011*, M.o.H.a. Population, Editor. 2012: Kathmandu, Nepal.; <sup>3</sup> Eide, A., S. Neupane, and K.G. Hem, *Living conditions among people with disability in Nepal*. 2016, SINTEF; <sup>4</sup> Alkire, S. and M.E. Santos, *Acute multidimensional poverty: A new index for developing countries*. 2010; <sup>5</sup> World Health Organization. *Monitoring Sustainable Development Goals*. Health financing for universal coverage 2017; Available from: [http://www.who.int/health\\_financing/topics/financial-protection/monitoring-sdg/en/](http://www.who.int/health_financing/topics/financial-protection/monitoring-sdg/en/).<sup>6</sup> Rutstein, S.O. and S. Staveteig, *Making the Demographic and Health Surveys Wealth Index Comparable*, in *DHS Methodological Reports* 9. 2014, USAID: Rockville, Maryland, USA.

## Supplementary File 2. Robustness testing

Four alternative MPI structures were tested, which varied in the construction of indicators and the weights assigned to dimensions/indicators.

Differences in the adjusted headcount ratio were then compared across the four indexes between people with and without disabilities at different cut-off points  $k$ .

### Measure 1

<i>Dimension</i>	<i>Indicator</i>	<i>Indicator weight</i>
Livelihoods	Work & education	1/10
	Food security (cut-off severe in Nepal)	1/10
Social inclusion	Voting	1/10
	Decision-making	1/10
Access to services	Water	1/15
	Sanitation	1/15
	Healthcare	1/15
Health and well-being	Health event	1/10
	Violence	1/10
Living conditions	Cooking fuel	1/20
	Flooring	1/20
	Overcrowding	1/20
	Assets	1/20

### Measure 2

Dimension	Indicator	Weight
Social inclusion	Voting	1/15
	Decision making	1/15
	Violence	1/15
Access to services	Water	1/10
	Sanitation	1/10
Health and nutrition	Healthcare	1/15
	Health event	1/15
	Food security (cut-off mild in Nepal)	1/15
Housing	Cooking fuel	1/15
	Flooring	1/15
	Overcrowding	1/15
Livelihoods	Work and education	1/10
	Assets	1/10

### Measure 3

Dimension	Indicator	Weight
Social inclusion	Voting	1/13
	Decision making	1/13
	Violence	1/13
Access to services	Water	1/13
	Sanitation	1/13
Health and nutrition	Healthcare	1/13
	Health event	1/13
	Food security	1/13
Housing	Cooking fuel	1/13
	Flooring	1/13
	Overcrowding	1/13
Livelihoods	Work and education	1/13
	Assets	1/13

### Measure 4:

Dimension	Indicator	Weight
Social inclusion	Voting	1/12
	Decision making	1/12
	Violence	1/12
Access to services	Water	1/12
	Sanitation	1/12
	Healthcare	1/12
Health and nutrition	Health event	1/8
	Food security – restricted to severe in Nepal	1/8
Housing and livelihoods	Assets	1/12
	Work and education	1/12
	Overcrowding	1/12

### Adjusted headcount ratio (MPI/M<sub>0</sub>) for different MPI structures and *k* cut-offs in Vietnam and Nepal

	Measure 1			Measure 2			Measure 3			Measure 4		
<i>k</i> (%)	All	PWD	ND	All	PWD	ND	All	PWD	ND	All	PWD	ND
<b>NEPAL</b>												
60	0.010	0.020*	0.000	0.056	0.099***	0.013	0.049	0.085***	0.013	0.000	0.000	0.000
55	0.025	0.047**	0.003	0.077	0.131***	0.022	0.049	0.085***	0.013	0.006	0.0124*	0.000
50	0.040	0.074***	0.006	0.114	0.178***	0.049	0.089	0.146***	0.032	0.025	0.047***	0.003
45	0.064	0.103***	0.025	0.144	0.217***	0.070	0.144	0.217***	0.071	0.032	0.059***	0.005
40	0.095	0.153***	0.038	0.203	0.282***	0.123	0.144	0.217***	0.071	0.058	0.100***	0.016
35	0.121	0.187***	0.055	0.222	0.303***	0.141	0.214	0.289***	0.138	0.076	0.123***	0.029
30	0.170	0.243***	0.096	0.281	0.353***	0.209	0.279	0.352***	0.205	0.113	0.172***	0.054
25	0.209	0.278***	0.141	0.297	0.365***	0.229	0.279	0.352***	0.205	0.135	0.194***	0.076
20	0.243	0.305***	0.181	0.333	0.390***	0.275	0.321	0.378***	0.263	0.173	0.229***	0.116
15	0.266	0.318***	0.214	0.340	0.395***	0.012	0.339	0.389***	0.287	0.196	0.249***	0.144
10	0.276	0.325***	0.228	0.348	0.400***	0.297	0.339	0.389***	0.287	0.211	0.259***	0.163
<b>VIETNAM</b>												
40	0.034	0.068***	0.000	0.016	0.033**	0.000	0.009	0.017*	0.000	0.029	0.056***	0.003
35	0.052	0.099***	0.005	0.028	0.057***	0.000	0.028	0.056***	0.000	0.046	0.089***	0.003
30	0.086	0.165***	0.007	0.048	0.090***	0.006	0.049	0.092***	0.007	0.053	0.101***	0.005
25	0.105	0.185***	0.026	0.056	0.097***	0.014	0.049	0.092***	0.007	0.109	0.181***	0.036
20	0.128	0.209***	0.047	0.099	0.164***	0.035	0.099	0.164***	0.035	0.124	0.201***	0.048
15	0.143	0.225***	0.061	0.117	0.183***	0.052	0.127	0.195***	0.059	0.143	0.220***	0.066
10	0.161	0.240***	0.083	0.139	0.202***	0.076	0.127	0.195***	0.059	0.148	0.225***	0.072