Measuring Disability in Population-Based Surveys: The relationship between *clinical impairments, self-reported functional limitations* and *equal opportunities* in two Low and Middle Income Country settings

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Declaration

I, Islay Ziya Mactaggart, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Student Signature:  Date: 31.01.2018

Abstract

Background:

Measuring disability in population-based surveys is imperative to support the meaningful inclusion of persons with disabilities in their societies.

Disability is a complex bio-psycho-social phenomenon incorporating dysfunctioning in any of three interlinked levels (impairments in body function or structure, activity limitations or participation restrictions), resulting from the interaction between a health condition and contextual factors. There is little consensus on how to measure different components of disability in population-based surveys, or how these components inter-relate. A comprehensive population-based methodology is needed to be able to assess the prevalence and lived experience of disability, incorporating the three levels at which dysfunctioning occurs.

Study Aim:

To develop and undertake a comprehensive population-based survey methodology of disability in two settings and i) use this to explore the inter-relationship between tools measuring different components of disability ii) assess the prevalence and iii) lived experience of disability, including predictors of inclusion.

Methods:

A scoping review of the literature was undertaken to inform the development of an all-age population-based survey of disability. Population-based surveys (n=4080) of disability incorporating measures of impairment (vision, hearing, musculoskeletal, depression), activity limitation (Washington Group Extended Set) and participation restrictions (SINTEF participation module) were undertaken in one district each of Cameroon (North West Region, 2013) and India (Telangana State, 2014). A nested case-control study of people with and without disabilities was undertaken, to identify predictors of inclusion (e.g. access to health and rehabilitation, education, livelihoods).

Key Findings:

Overall disability prevalence was 12.2% (India) and 10.5% (Cameroon). Approximately 40% of people in each setting who screened positive for a clinical impairment did not report a functional limitation. A self-reported functional limitation tool followed by clinical screening of all those who report any level of difficulty would identify 94% of persons with disabilities in Cameroon and 95% in India, meeting the study criteria. Persons with disabilities in both settings experienced unequal opportunities. Children with disabilities were at least ten times less likely to be enrolled in education than children without disabilities; whilst adults with disabilities were five times less likely to be working than adults without disabilities, and between twice (Cameroon) and three times (India) more likely to have experienced a significant health problem in the past year.

Conclusion:

This study provides a suggested way forward for the measurement of disability in population-based surveys that would support the meaningful inclusion of persons with disabilities in their societies.

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Table of Contents

List of Tables

Tables in Paper One

Tables in Paper Two

Tables in Paper Three

Tables in Paper Four

Tables in Paper Five

Abbreviations

ABR	Auditory Brainstem Response
ACPF	African Child Policy Forum
ASHA	Accredited Social Health Activists
CI	Confidence Interval
CMD	Common Mental Disorder
CSI-D	Community Screening Instrument for Dementia
DALYS	Disability Adjusted Life Years
DASH	Diagnostic Assessment for the Severely Handicapped
DBA	a-weighted decibels
dbHL	Decibel Hearing Level
DHS	Demographic and Health Survey
DPO	Disabled People's Organisation
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSQ34	Disability Screening Questionnaire
ECDD	Ethiopian Center for Disability and Development
EFA	Education for all
ENT	Ear, Nose and Throat
ES-F	Extended set on functioning
GBD	Global Burden of Disease study
GHQ-12	General Health Questionnaire
GNI	Gross National Income
HADS-D	Hospital Anxiety and Depression Questionnaire
HDI	Human Development Index
HICs	High Income Countries
ICD-10	International Statistical Classification of Diseases and Related Health Problems
ICED	International Centre for Evidence in Disability
ICF	International Classification of Functioning, Disability and Health
ICF CY	International Classification of Functioning, Disability and Health Child and Youth Version
IIPHH	Indian Institute of Public Health, Hyderabad

IQ	Intelligent Quotient
IRT	Item response theory
Kz	Kilo-hertz
LMIC	Low and Middle Income Country
LSHTM	London School of Hygiene & Tropical Medicine
MDS	Model Disability Survey
MICS	Multiple Indicator Cluster Surveys
MSI	Musculoskeletal Impairment
NCD	Non communicable disease
NHS	National Household Survey
NPV	Negative Predictive Value
OAE	Oto-Acoustic Emissions
PCA	Principal component analysis
PHFI	Public Health Foundation of India
PHQ-9	Patient Health Questionnaire
PIMRA	Psychopathology Instrument for Mentally Retarded Adults
PL	Perception of light
PPV	Positive Predictive Value
PTA	Pure Tone Audiometry
RAAB	Rapid Assessment of Avoidable Blindness
RAD	Rapid Assessment of Disability
RAM	Rapid Assessment of Musculoskeletal Impairment
SDA	Sustainable Development Agenda
SDGs	Sustainable Development Goals
SEEPD	Socio-Economic Empowerment of Persons with disabilities
SERP	Andhra Pradesh Society for Elimination of Rural Poverty
SES	Socio-economic status
SRQ-20	Self Reported Questionnaire
SS-F	Short Set on Functioning
TQ	Ten Questions Tool
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund

VA	Visual Acuity
WASH	Water, Sanitation and Hygiene
WG	Washington Group
WHO	World Health Organisation
WHO/PBD	World Health Organisation Prevention of Blindness and Deafness Programme
WHODAS	World Health Organisation Disability Assessment Schedule
WHS	World Health Survey

Structure of Thesis

This thesis is formatted in the "**Research Paper Style**".

Chapter One provides an overview of disability in the context of global health. Previous frameworks and the prevailing conceptualisation of disability are explored in Section 1.1 before summarising available data on the magnitude of disability in Section 1.2. Evidence on the association between disability and major life areas including education, livelihoods, health and poverty are explored in Section 1.3. The implications of these associations and the need to collect population-based data on disability are summarised in relation to the 2015 – 2030 Sustainable Development Agenda in Section 1.4, followed by an overview of the principles of disability measurement in Section 1.5.

Chapter two states the research question, aim and objectives.

Chapter three provides a critical review of the literature in relation to the measurement of disability in population-based surveys, which provides the rationale for the choice of tools used in the population-based surveys undertaken as part of this research.

Chapter Four documents the field research methodology in Cameroon and India (in each, a district-level population-based survey with nested case-control study) and is complemented by **Chapter Five** – a research publication (***Paper One***) describing the development and further testing of one tool (the UNICEF/ Washington Group Extended Set on Functioning for Children) as part of the research.

Chapter Six (***Paper Two***) presents the results of the population-based surveys, including prevalence estimates and the inter-relationship between tools used to measure components of disability through objective impairment screening and reported functional limitation. **Chapter Seven** provides additional results on the prevalence of specific impairments and functional limitations. **Chapter Eight** provides additional data on the inter-relationship between each impairment and the corresponding reported functional limitation domain.

Chapters Nine to **Eleven** (***Papers Three*** to ***Five***) report on the findings of the nested case-control studies, including the association of disability with health, education and livelihoods, and on predictors of association amongst persons with disabilities.

Chapter Twelve summarises the findings and discusses the implication of the results for policy, programmes and future research.

Appendix 1 includes additional impairment prevalence papers prepared for submission but not included in the thesis, whilst **Appendices 2 – 6** provide additional documents related to study questionnaires and fieldwork.

Chapter One: An introduction to disability

1.1 Disability Concepts and Models

In contrast to clear, objective classifications that can be used to determine the presence of most health conditions and outcomes of interest in global health, the concept of disability is complex, contested, and has evolved over time. This conceptualisation is of fundamental importance well beyond the realms of academic debate. The limited available data globally show clearly that disability affects a large proportion of the global population, and that many persons with disabilities, particularly in Low and Middle Income Countries (LMICs), are denied their right to equal opportunities and meaningful inclusion in their societies[2]. Few data on disability are available, and the data that exists is inconsistent. A clear, common understanding of what disability means, and the population this refers to, is therefore imperative in working towards removing barriers to participation and increasing equality of opportunities for persons with disabilities.

Early understandings of disability within ancient and religious literature perceived disability predominantly in terms of bodily and intellectual impairment, using terms such as “disfigured”, “feeble-minded” and “lame”[3]. Causality was ascribed to divine intervention, either following previous sin or wrong-doing or to challenge the individual, whilst simultaneously promoting a charitable approach in supporting the “sick” or “infirm”[3, 4]. Examples of this are found throughout religious text, giving rise to the marginalisation of persons with disabilities on account of stigma and perceived “otherness” [4]. Arguably, a charitable model is still being used in certain development assistance discourses, but should be considered inappropriate, on account of the fact that it does not acknowledge human rights or capacities [5, 6]. For example, a programme that donates clothes or other goods to the family of a person with a disability, but does not seek to support him/her in acquiring their own means of supporting themselves or their family, would be defined as a charity model approach.

Disability continued to be understood as bodily and intellectual disadvantage until the mid-modern period, particularly in the context of the industrial revolution and the perceived inability of persons with disabilities to engage productively in factory work[7]. This era led to the increased incarceration of persons with disabilities in

institutions, who were categorised along crude lines such as “defectives”, “mentally sub-normal” and “aged or infirm”, and to dehumanising arguments and activities around eugenics and forced sterilisation [8].

Scientific advancements in bio-medicine in the mid to late 19th century, such as development of modern hospitals and laboratories, formalised this medical model of disability (also known as the individual model) [9]. This model, which developed within the broader context of bio-medical narratives of health and disease, focusses on the presence of bodily impairments – such as in vision or mobility – in defining persons with disabilities. For example, a person who, through clinical assessment, is perceived to be blind, or who has paraplegia, is automatically considered to have a disability. This model prioritises medical and rehabilitative interventions designed to ameliorate health conditions and impairments. However, it does not recognise the external factors contributing to the lived experience of disability – for example lack of environmental accommodation or societal stigma – or the non-medical support that may benefit a person with an impairment, including educational or vocational support[10, 11]. Moreover, given that decision-making on disability presence is entirely in the hands of the medical practitioner, the model has been criticised by disability scholars for diminishing the importance of the individual’s perspective and identity in relation to their impairment [12].

In contrast, the social model of disability – led by representatives of Disabled People’s Organisations (DPOs) and academics – was conceived in the United Kingdom in 1976 following the publication of “*The Fundamental Principles of Disability*” by the Union of the Physically Impaired Against Segregation[13]. This model challenges the medical model and its role in perpetuating oppression and exclusion of persons with disabilities[14, 15]. The social model seeks to emancipate the term disability from impairment, and to focus on the social exclusion, cultural stigma and environmental barriers which disable persons with impairments and deny them their basic rights [14, 16]. For example, emphasising the role of inaccessible buildings in disabling an individual with paraplegia. Oliver (2013) argues that the return on investment in interventions at the level of the individual (such as physical rehabilitation for an individual with a mobility impairment) are necessarily lower than returns on interventions at the societal level (such as

replacing stairs with ramps) that diminish disablement imposed on all persons with mobility impairments [16].

However, critiques of the social model include its disproportionate focus on physical impairments above mental health, sensory or cognitive impairments, and its limited focus on the role of the underlying health condition or impairment itself in the disablement process [5, 14]. For example, clubfoot is a congenital developmental condition affecting 100,000 births annually, the majority in LMICs[17]. Uncorrected clubfoot can cause significant, lifelong physical impairment, but can be easily corrected using non-surgical Ponseti treatment. A social model approach would be to focus on ensuring an accommodating environment for a child with a physical impairment, rather than on approaches that can minimise the impairment itself. However, a focus on impairment may directly improve functioning and support the child's participation in a different way.

More recently, the International Classification of Functioning, Disability and Health (ICF) was endorsed by the 54th World Health Assembly in 2001. The ICF reflects the World Health Organisation (WHO)'s growing prioritisation of the causes and incidence of global morbidity, and was developed to complement the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [18, 19]. The ICF identifies three universal levels of human functioning –body functions and structures, activity and participation – which are defined in Table 1 below.

Table 1: ICF Classifications of human functioning [20]

Body Functions and Structures	Physiological functions of body systems and anatomical parts of the body and their components
Activity	Executions of a task or action by an individual (e.g. washing, toileting, walking)
Participation	Involvement in a life situation (e.g. attending school, working, partaking in community events)

According to the ICF, disability is an umbrella term encompassing dysfunctioning at one or more of these three interlinked levels as the result of the interaction between a health condition and contextual factors. Levels of dysfunctioning refer to

impairments in body structure or function at the level of the body, activity limitations at the level of the person, and participation restrictions at the level of society [18]. Contextual factors that mediate the interaction between the health condition and dysfunctioning at each level are sub-divided into environmental and personal factors. Environmental factors are defined as *"the physical, social and attitudinal environment in which people live out and conduct their lives".* Examples include whether people have access to assistive devices and technology, the accessibility of the built and natural environments and the inclusivity of policies and programmes. Personal factors are not defined in the ICF, but according to the WHO include *"gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual*" [21]. Altogether, the outcome of this interaction determines the individual's "*lived experience of disability*" – i.e. what they are able to do in their current context[18].

A child and youth specific version of the ICF, the ICF-CY, followed in 2007[22]. The ICF-CY follows the same principles as the ICF, but expands to accommodate the diversity of capacities amongst children from infancy to adolescence, and in relation to variation across developmental phases[22, 23].

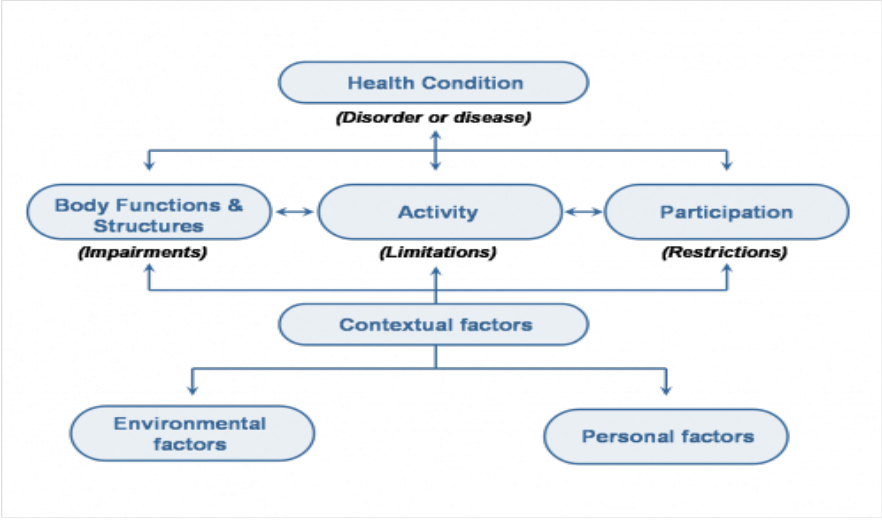


Figure 1: The ICF Framework. Source: Rehab-scales.org

This lived experience of disability approach combines elements of both the biomedical and social model approaches and is thus termed a *bio-psycho-social* model of disability and health (Figure 1) [24-27]. Table 2 further articulates the ICF,

using the example of long term sequelae of meningitis. Meningitis is a health condition that can cause permanent conductive hearing loss (impairment), affecting a child's ability to hear and listen (activity limitations). In the absence of an enabling environment, this can limit the child's opportunities to learn in their local school (participation restrictions). Disability is the umbrella term encompassing the child's experience of functioning at each of these levels (impairments, activity limitations and participation restrictions) both as a result of having acquired meningitis and as a result of contextual factors such as the child's access to hearing aids (environmental factors) or resilience (personal factors).

Table 2: Defining the ICF model of disability

Component of ICF definition of disability	**Perspective**	**ICF Definition**	**Example – long term meningitis sequelae**
Impairments in body function or structure	Body	Impairments in physiological functioning or anatomical parts of the body	Conductive hearing loss
Activity Limitations	Individual	Limitations in the execution of tasks or actions by an individual	Difficulty hearing
Participation Restriction	Society	Problems experienced in involvement in life situations	Ability to learn in local context
Personal Factors	Overall	*Not defined in the ICF*	Resilience
Environmental Factors	Overall	The physical, social and attitudinal environment in which people live and conduct their lives	Assistive Device Service Provision

Source: Adapted from "*Towards a Common Language for Functioning, Disability and Health, ICF*" WHO (2002)

In contrast to the social model, the ICF recognises the role that the underlying health condition, and impairments this may cause at the level of the body, play in the disablement process. However, an important distinction of the ICF in contrast to the charity and bio-medical models, is that the presence of a health condition or impairment *in isolation* is not considered a proxy for disability. For example, a child

determined to have a bilateral profound hearing impairment cannot be assumed to have a disability (or labelled as such) without understanding whether there is a negative impact of the impairment on the child's activities or participation in his or her environment. Whether or not the child has access to assistive devices or quality inclusive education that meets his or her needs, necessarily impacts on whether the underlying health condition or impairment is disabling.

A second essential distinction of the ICF is the conceptualisation of disability as a process, whereby the interactions between the components of the framework lead to a given state of disablement. This state of disablement – the current lived experience of disability – is subject to change in accordance with changes across all components of the framework, and is therefore both temporal and situational. Mitra (2006) further explores this from the perspective of Sen's Capability Approach[28]. In applying the Capability Approach to the conceptualisation of disability, she differentiates between capabilities (what the person is capable of achieving in the presence of full accommodation) and performance (what the person is capable of achieving in their current environment)[29].

In tandem with the formalisation of the ICF, a human rights framework for disability has focused on the universal rights of persons with disabilities – as all persons – to equality and justice[30]. The slogan "nothing about us without us" captures the activism led by persons with disabilities towards the creation of a United Nations Convention on the protection of the rights of persons with disabilities[30]. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force in 2006, and whilst not explicitly stated, the ICF is also considered the underlying framework in the definition of disability incorporated within it [31]:

"Persons with disabilities include those 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."

Article 1, UNCRPD

The UNCRPD, which as of April 2017 has been ratified by 172 state parties, is an internationally binding human-rights instrument mandating signatories to ensure

the full participation, non-discrimination and equality of opportunity for persons with disabilities in all realms of life, including health, education and livelihoods[31]. Whilst the rights of all people are enshrined within all international human rights treaties, and no new rights or entitlements are created in the UNCRPD, its purpose is to explicitly reaffirm and reinforce respect for the rights of persons with disabilities, given their continued widespread exclusion and oppression[32]. This is further reinforced by the recently launched 2030 Sustainable Development Agenda, which pledges to "*leave no-one behind*" (see Section 1.4) [33].

The ICF is not without its own criticism. Tøssebro (2004) – alongside other social model proponents– theorises disability as a relational mis-match between the individual's capacities and their current environment, emphasising the need to focus policy intervention on the latter, as opposed to focusing on the individuals[34, 35].

Despite the above critiques, the ICF is considered the prevailing model of disability. Consequently, the ICF conceptual framework will be used throughout this thesis, with the term "*persons with disabilities*" referring to individuals experiencing body function/structural impairments, activity limitations or participation restrictions as the result of the interaction between a health condition and contextual factors.

1.2 The global magnitude of disability

There is substantial variation in estimates of disability magnitude and prevalence across countries and over time[2]. This is, in part, a consequence of the differing conceptual definitions of disability and measurement approaches employed by previous disability data collection efforts. However, there have been two major, coordinated efforts to produce global estimates of the magnitude of disability: the World Health Survey (WHS, 2004) and the meta-data Global Burden of Disease (GBD) study. In addition, the World Report on Disability, produced by the WHO in 2011, compiled available scientific evidence on disability and synthesised these separate efforts to estimate a global prevalence of disability[2].

The WHS – the largest global dataset on disability in adults aged 18 and above –

generated data on disability across 70 countries between 2002 - 2004 [2]. Disability estimates were derived via participant self-report on functional limitations in domains related to affect, cognition, interpersonal relationships, mobility, pain, sleep and energy, self-care and vision. On account of previous study findings that showed poor sensitivity and specificity in self-reported hearing function, this domain was excluded, implying potential underestimation in the overall disability estimate[36]. The World Report on Disability pooled WHS data from 59 countries to estimate disability prevalence by country, region, age group and gender[37]. To accommodate multiple functional limitations, responses across all domains were aggregated to create a composite score. Item Response Theory and Rasch modelling were then used to transform each score to a number between 0 (no difficulty) and 100 (complete difficulty). Based on this analysis, and on the average scores of participants with selected chronic "*indicator conditions*" such as arthritis and angina, participants with a score of 40 or above were considered to have a "*significant difficulty*" and a score of 50 or above considered "*very significant difficulty*"[2]. According to these thresholds, the all-country prevalence of significant difficulty was 15.6% (11.8% in High Income Countries (HICs) and 18.0% in LMICs) and of very significant difficulty was 2.2% (HICs in 2.0% and LMICs 2.3%). Substantial variations in the country prevalence estimates, weighting of non-nationally representative datasets and the inclusion of only two datasets from HICs are all noted limitations of these estimates[37].

The Global Burden of Disease (GBD) study, an epidemiological meta data-analysis, takes a different approach. The GBD calculates Disability-Adjusted-Life-Years (DALYS) using statistically calculated disability weights for years of life lost to, and spent living with, 310 causes of disease and long-term sequalae [38]. Estimates by GBD collaborators in 2015 are based on meta-analyses from 591 locations and a variety of data sources including population-based epidemiological surveys, hospital data and disease registries. Complex modelling allows estimation of the incidence and prevalence of each cause by severity and sequelae, the weight of each of which is computed on a continuum between 0 (equivalent to full health) and 1 (equivalent to death)[38]. Using this methodology, the authors report that 10.5% of

men and 11.4% of women globally will live with disabilities, with the proportion of the population experiencing more severe disabilities increasing with age group[1].

The GBD figures are updated each decade, and arguably provide important detail on global epidemiological transitions linked to disability – such as the implication of decreasing global mortality rates and ageing populations, or the effects of the diabetes and dementia epidemics – on disability prevalence. However, the estimates have been criticised for the narrow focus on loss of health without accounting for the lived experience of disability in the context of environmental or personal factors as incorporated in the ICF [39]. From a human rights perspective, DALYs devalue the lives of persons with disabilities through equating the presence of a health condition or impairment to a lower valued existence, arguably increasing discrimination and stigma [40]. In addition, the complexity of modelling required to conduct the meta-analyses and the inherent biases caused by absent or poorly collected primary data are acknowledged as methodological limitations by the GBD collaborators [41].

Robust global estimates on the magnitude of disability in children are even more limited. It is widely reported that there are approximately 93 – 150 million children living with disabilities worldwide [42]. However, it is less widely reported that the 93 million statistic originated from "inconsistent, fragmented and partial data" as part of the 2004 GBD update over a decade ago [41]. Similarly, the 150 million statistic derives from the 2006 UNICEF State of the World's Children Report, which does not provide the source of this figure [43]. Moreover, epidemiological transition, including declining under-five mortality rates and increasing global coverage of neo-natal services, suggest that the proportion of children living with disabilities globally may be increasing, which is not captured by these dated estimates [44].

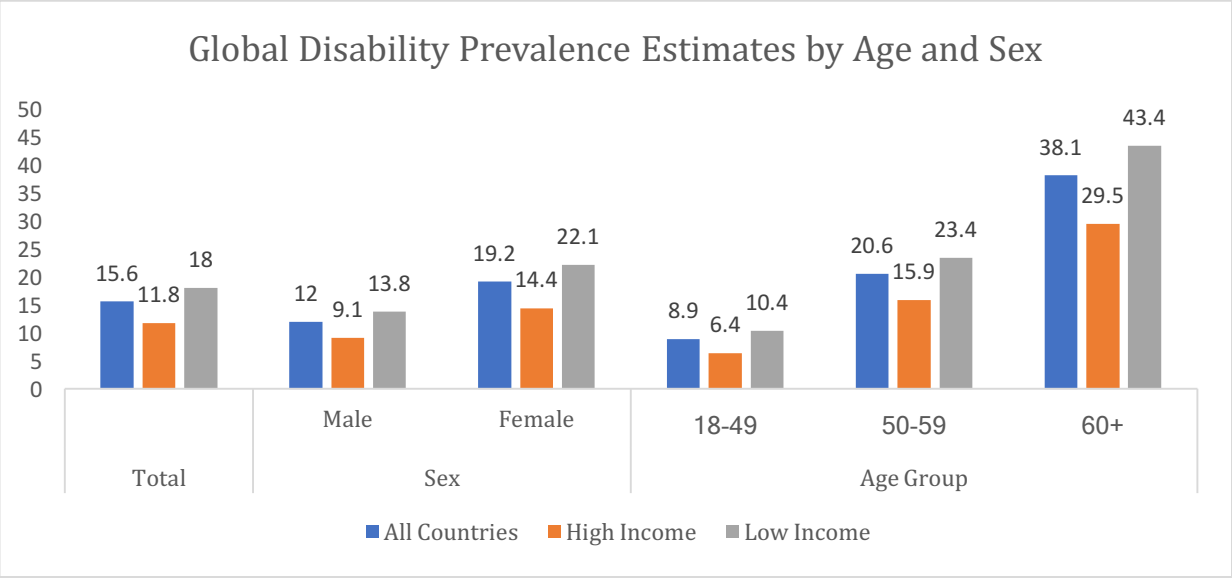
A second source of data on child disability is the inclusion of the Ten Questions (TQ) tool in UNICEF-supported Multiple Indicator Cluster Surveys (MICS) since 2000. The

[1] Estimates from Supplementary Appendix provided with Vos et al. (2015) available from: http://www.thelancet.com/cms/attachment/2081614035/2072505583/mmc2.pdf

TQ was designed to identify children aged 2-9 years at risk of disability via parental response. A recent review undertaken by Cappa et al. (2015) identified child disability estimates from MICS in 26 countries ranging from 3 – 48% [45]. However, the original authors of the tool have previously cautioned of up to four-fold over-reporting of disability when using the tool as a screen, and the need for a second stage assessment (i. e. clinical assessment verification) to verify or reject findings [46].

Currently, the most often cited global prevalence of disability is 15% of the global population, comprising an estimated one billion people. This estimate was calculated using pooled WHS and GBD data from 2004 in the World Report on Disability (2011)[2]. The report used population demographics from the same year to extrapolate the estimate to include children [2].

Graph 1 below depicts the demographics of global disability estimates calculated in the World Report on Disability (2011) [2]. Disability estimates for low income countries are higher than for high income countries overall and after stratification by age and gender. Disability was found to be higher in women than men on aggregate, and to be positively associated with ageing.



Graph 1: Global Disability Prevalence Estimates by Age and Sex

In summary, there have been several efforts to assess the global magnitude of disability, with caveats to each approach. There is a lack of evidence from recent data collection activities, and in particular from population-based surveys, using comprehensive methodologies to determine the prevalence of disability as defined in the ICF.

1.2.1 Causes of Disability

Determining the "cause" of disability is equally challenging, given the complex definition of the term and the interaction between the individual and external factors that contribute to the lived experience of disability. More appropriate is to determine the types of underlying health conditions and impairments that heighten risk of disability. For example, the GBD (2015) estimates the three most prevalent all-age global causes of years lived with disability to be lower neck and back pain, sense organ diseases and depressive disorders respectively [38].

In addition, a substantial literature on the prevalence of specific health conditions and impairments exists. Impairments included in the UNCRPD definition of disability are physical, mental, intellectual or sensory impairments (impairments in vision or hearing). Estimates released by the WHO Prevention of Blindness and Deafness programme in 2011 indicated that the global magnitude of moderate or worse visual impairment includes 285 million people, 39 million of whom are blind [47]. Similarly, a review of 42 studies by Stevens et al. (2013) estimated a global magnitude of moderate or worse hearing impairment in males aged fifteen or above of 299 million (8.4%), in addition to 6.8% (239 million) of females[48]. The magnitude of musculoskeletal impairments (MSI) is more difficult to estimate given the heterogeneity of conditions related to MSI, and absence of robust population data in this area, but is also considered to be substantial, particularly in LMICs [49]. In addition, Kessler et al (2011) analysed data from 17 WHO World Mental Health Surveys of adults 18 and above. The inter-quartile range of the prevalence of lifetime mental disorders (anxiety, mood, disruptive behaviour, and substance use disorders) was 18.1 – 36.1%.

These estimates provide important data to support planning appropriate services to maximise functioning amongst persons with disabilities. However, these studies and reviews tend to investigate a particular impairment or health condition in isolation, rather than estimating functioning of the person as a whole. Thus, few assess the implications of health conditions or impairments on activity limitations or participation restrictions, or the diverse support requirements two people with the same impairment may have, providing an incomplete picture of disability.

1.3 The Lived Experience of disability

Despite the widespread ratification of the UNCRPD, the limited existing literature suggests that the rights of persons with disabilities – broadly, to full participation, non-discrimination and equality of opportunity – are frequently not being realised around the world. Ensuring equality of opportunities for persons with disabilities is consequently both a human rights and global development issue. This is particularly important in the context of LMICs, where both prevalence of disability and barriers to inclusion are greatest [37, 50]. The following review illustrates the association between disability and major life areas – namely education, livelihoods and health. An overview of the association between disability and poverty is also included given the relevance in LMICs. Whilst it is recognised that there may be associations between disability and all domains of life (for example political participation, or participation in leisure activities), a comprehensive review of this literature is beyond the scope of the present study.

1.3.1 Disability and Education

Although the right to education is enshrined in Article 24 of the UNCRPD, there is evidence that children with disabilities continue to be excluded from education far more than their peers. Kuper et al. (2014) analysed data relating to almost 900,000 children across thirty countries, estimating that children with disabilities were between five and twenty times less likely to be enrolled than children without disabilities in all but seven of the included settings[51]. Stratified analysis showed that children with learning or communication impairments were frequently the

most likely to be excluded. Similarly, Mizunoya et al. (2016) analysed data from 18 nationally-representative surveys across fifteen LMICs[52]. A statistically significant disability enrolment gap, namely the crude difference in percentage points between the percentage of school-aged children with and without disabilities out of school, was identified in each data-set. The disability gap ranged from 3.1 percentage points in South Africa to 55.1 percentage points in Albania and rose in parallel with Gross National Income (GNI), suggesting rising inequalities in access to education with increasing income. This therefore suggests that school attendance for children without disabilities increases as a country's income increases, but not for children with disabilities, who are left behind. This analysis quantifies the concept that mainstream development progress that is not inclusive "widens the gap" between persons (including children) with and without disabilities[53].

1.3.2 Disability and Livelihoods

Similar trends are seen in terms of livelihoods. Livelihoods can be defined as the mechanisms through which households and individuals are able to meet their basic needs [54]. Livelihoods encompass remunerated labour in addition to a broader understanding of the person's capabilities (for example level of education or skill set), capacity to access assets and participation in other productive activities such as subsistence farming [54].

Evidence from WHS data from fifteen LMICs identified a statistically significant disability employment gap (calculated via the same approach as the disability enrolment gap) amongst adults aged 18-60 in nine of the fifteen included countries[50]. The gap ranged from 6 to 25 percentage points, and was higher amongst men with disabilities. However, complex livelihoods in LMICs – such as informal activities, exchange in kind, subsistence agriculture and seasonality fluctuation in work – may not be captured by constricted formal employment variables[2], potentially underestimating the true size of the gap [55]. Using a similar survey methodology, Trani and Loeb (2012) showed that adults with disabilities in

[2] Main employment status question in WHS: "*Now, I would like to ask you a few questions about your work status. What is your current job? 1- Government Employee; 2- Non-Government Employee; 3- Self-Employed; 4- Employer; 5- Not Working*"

Afghanistan and Zambia were five times and twice as likely not to be working respectively, compared with adults without disabilities[56].

1.3.3 Disability and Health

Evidence suggests that persons with disabilities are generally at higher risk of serious health episodes than persons without disabilities, both in relation to the underlying health condition related to their disability, and in terms of general health. Analysis from the WHS identified consistently higher in- and outpatient health-seeking amongst persons with disabilities compared to persons without[2]. Similarly, Kuper et al.'s analysis across thirty countries found that children with disabilities experienced more frequent episodes of serious illness than children without disabilities, including both impairment-related illness (such as vision or hearing problems) and general illnesses (including malaria or respiratory infection)[51].

Frequent ill-health has been linked to catastrophic health costs – namely those which are *"likely to force households to cut their consumption of other minimum needs, trigger productive asset sales or high levels of debt, and lead to impoverishment"* – and may be one of many pathways through which persons with disabilities are excluded from education and employment [57, 58]. Moreover, a number of studies have identified greater barriers to accessing health services amongst persons with disabilities when they do experience poor health. For example, a recent study by Eide et al. (2015) across four African settings, determined a higher probability of not receiving health care amongst persons with disabilities compared to intra-household controls[59]. Probability of accessing health-care amongst persons with disabilities in the study decreased with increasing functional limitations, and increasing age in all settings.

1.3.4 Disability and poverty

A fundamental area for consideration in terms of the lived experience of disability, is the relationship between disability and multidimensional poverty (economic and non-economic measures of deprivation, such as food insecurity and low access to

education or work), which is perceived to be cyclical, as depicted in Fig. (below)[60], and may underlie many of the exclusions experienced.

As seen in Figure 2 and from the literature summarised above, disability is often associated with catastrophic health costs, and denial of opportunities to learn, work, and participate equally in society, heightening the risk of poverty. Equally, poverty is in itself a cause of participation restriction, and is associated with heightened risk of disability, via several causal pathways (described below) including exclusion from health and rehabilitation services, and increased exposure to risk factors of poor physical and mental health.

Figure 2: The Theoretical Relationship between disability and poverty, Source: DFID (2000)

In terms of physical health, many of the so-termed "diseases of poverty", including HIV/AIDS, the majority of Neglected Tropical Diseases (such as lymphatic filariasis, leishmaniasis, buruli ulcer, onchocerciasis, leprosy and trachoma), peri-natal and maternal conditions, and nutritional deficiencies, can have long term implications on ill-health and impairment[61, 62]. Poverty has also been empirically linked with heightened non-communicable disease (NCD) risk through tobacco use, poor diet and alcohol consumption, leading to diseases with long-term impairment sequalae

such as cardiovascular disorders and diabetes [63]. In addition, a recent review of the association between poverty and common mental disorders (CMDs, namely depression, anxiety and somatoform disorders) determined positive association between various poverty measures and CMDs in 79% of the studies included [64].

People living in poverty have also been shown to have lower access to public health interventions (for example, immunisation), lower access to improved water and sanitation facilities, heightened environmental risks (such as unsafe work environments or transport options) and injuries, all of which are associated with risk of long-term impairment and disability [65, 66].

A recent systematic review by Banks and Keogh (2016) showed a positive association between disability and economic poverty in LMICs in 80% of the 98 included studies[67]. Similarly, Mitra et al. (2013) used WHS data to undertake a comparative analysis of multi-dimensional poverty and disability in the working age population (aged 18-65), in 15 LMICs [65]. Persons with disabilities were more likely to be living in poverty (defined as deprived in at least four of ten included dimensions) in thirteen of the fifteen countries analysed, although the percentage point score difference was found to vary substantially from fifteen in Kenya to three in Burkina Faso. However, household-level poverty, measured in terms of poverty headcount[3], identified significant differences between households with and without at least one member with a disability in three settings only[65].

In summary, the available body of peer-reviewed empirical evidence points to negative associations between disability, poverty and restrictions from major life areas such as education, livelihoods and health, but data from LMICs are restricted to a small number of sources. Moreover, the considerable variation between methodologies used within existing datasets, and the duration of time since the largest dataset (the WHS) was collected, substantively limits comparability and usability over time.

[3] The number of families identified as poor, divided by the total number in the population of interest.

There is an urgent need for up-to-date, comprehensive data on the lived experience of disability using methodologies compatible with the ICF. These data are imperative to understand how many people there are with disabilities and the implications of disability on their lives. Only with this data can appropriate, evidenced-based advocacy and policy be constructed to fulfil the rights of persons with disabilities to non-discrimination, meaningful inclusion and equality of opportunity.

1.4 Disability and the Sustainable Development Agenda: the use of data to ensure no one is left behind

Over the last decade, a strong movement has emerged mandating the collection of comparable data on disability. Box 1 below provides the relevant calls from the UNCRPD (2006), the WHO World Report on Disability (2011), and the Sustainable Development Goals (SDGs, 2015) regarding disability disaggregated data collection [2, 31, 33]. Collection of these data are considered key for monitoring the implementation of the UNCRPD over time and to ensure meaningful inclusion of persons with disabilities in their societies.

As such, a comprehensive, agreed approach for the classification of "*persons with disabilities*", so as to conduct comparable population-based surveys of disability and monitor inclusive programmes, practice and opportunities for persons with disabilities, is important.

UNCRPD Article 31: Statistics and data collection (2006)

31. States Parties undertake to collect appropriate information, including **statistical** and **research data**, to enable them to **formulate** and **implement policies** to give effect to the present Convention.

World Report on Disability Recommendation 8: Improve disability data collection (2011)

- Develop standardised and internationally comparable data collection methodologies based on the ICF
- Include disability in national data collection efforts such as Census and administrative data, and consider dedicated disability surveys

Sustainable Development Goal 17.18: Data monitoring and accountability (2015)

17.18 By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to **increase significantly** the availability of **high-quality, timely** and **reliable** data **disaggregated by** income, gender, age, race, ethnicity, migratory status, **disability**, geographic location and other characteristics relevant in national contexts

Box 1: International disability data collection mandates

Several authors have postulated that the prior lack of agreed methodological approach to the identification of persons with disabilities has contributed to the limited attention previously paid to disability in the international development agenda, and a widening gap between people with and without disabilities in LMICs [65, 68]. In addition, the extremely complex and heterogeneous internal and external factors that impact on the lived experience of disability mandate the collection of data of sufficient methodological and statistical rigour on a country-by-country basis so as to develop appropriate policies and meet diverse needs.

In light of the need to establish an agreed methodological approach to the identification of persons with disabilities in population-based surveys, the next

section reviews principles of disability measurement that are compatible with the ICF.

1.5 Principles of disability measurement compatible with the ICF

In addition to the broad methodological approaches undertaken by the WHS and GBD discussed in the last section, a variety of other approaches have previously been used to measure disability in surveys and censuses. This section will summarise methodologies designed to capture one or more component of the ICF in population-based surveys.

1.5.1 Single direct question

An approach often used in in the past in censuses and large-scale population-based surveys has been to ask a single question on whether or not the person considers themselves to have a disability (see Box 2 for examples).

Single Census/Survey Questions on Disability

Example 1:
Q:"Do you have a disability?"
Response Categories: 1)Yes 2) No
[Source: Zambia Census 1990]

Example 2:
Q:"Do you have (serious) difficulty in moving, seeing, hearing, speaking or learning which has lasted or expected to last 6 months or more?"

Response Categories: 1) Yes, all the time 2) Yes, sometimes 3) No
[Source: Uganda National Household Survey 2005/2006]

Box 2: Single Census/Survey Questions

This approach is rapid and arguably attempts to capture the overall experience of disability. However, whilst disability is the umbrella term defined by the ICF, it cannot be presumed that participants utilise this definition when responding.

Instead, this approach would record those who self-identify as disabled based on their own pre-existing definition of the term, which may vary substantially across cultural, geographical or spiritual planes.

For example, whilst a large literature indicates decreasing functional capacities with age, this is often conceptualised by individuals as "*part of the ageing process*" rather than within a disability framework, and may not be captured using this approach [69]. Moreover, given the stigma associated with self-identifying as a person with a disability in many cultures, directly asking a respondent whether they have a disability is likely to substantially under-estimate the prevalence of disability as per the ICF definition [10, 68]. Consequently, this approach is generally not considered adequate for the collection of comparable disability data in population based surveys.

1.5.2 Reported functional limitations

A second approach, recommended by several International Agencies, is to assess both the *body structure or function* and *activity* components of the ICF (broadly, *functional limitations*) via self or proxy report. For example, asking an individual to report whether they have difficulties sleeping or remembering (body functions), or walking (activities) across an intensity response scale [70, 71]. This approach might include the question "*do you have any difficulty hearing*", with response options of "*no difficulty*", "*some difficulty*", "*a lot of difficulty*" and "*cannot do*".

Washington Group Short Set of Questions for Census

Preamble: "The next questions ask about difficulties you may have in doing certain activities because of a health condition.."

1. Do you have difficulty seeing even if wearing glasses?
2. Do you have difficulty hearing even if using hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Do you have difficulty communicating (for example, understanding or being understood)?

Response categories: 1)No difficulty 2)Some difficulty 3)A lot of difficulty 4)cannot do at all

Box 3: The Washington Group Short Set

Box 3 gives an example of such a tool – The Washington Group Short Set – designed by the Washington Group on Disability Statistics to assess self-reported functional limitations in national censuses[72]. The module has been endorsed both by the United Nations Statistical Division (2014) for the 2020 round of censuses, and as a minimum for monitoring inclusion under the UNCRPD and in the Sustainable Development Agenda (2016) [73, 74].

This approach is designed to *"identify persons at greater risk of experiencing participation restrictions than others through report of limitations in performing wilful or purposeful bodily or sensory actions"*[72]. Collecting data on self-reported functional limitations has a number of advantages. First, it avoids the stigma of direct questioning about disability. Second, it uses simple terminology on universal domains of functioning, and is therefore relatively straightforward to translate, providing standardised data and comparability of responses across time points and geographies. These data can be used to assess equalisation of opportunities for people with disabilities by comparing those who do or do not report functional limitations in terms of access to education or livelihoods and so on. Third, it captures the spectrum of dysfunctioning that two individuals with the same health condition or impairment may have depending on their context. For example, two adults with the same level of refractive error may report different levels of difficulty seeing depending on whether they are a farmer, or a desk-based worker. In addition, the use of frequency or intensity response scales provides information on the continuum of functioning that people may experience [75, 76]. Finally, reported functional limitation tools are relatively rapid and do not require clinically trained specialists to collect data, so surveys using these measures are comparatively low cost.

These data, however, may be limited in the extent to which they can inform planning and development of certain services and interventions designed to maximise functioning of affected individuals. For example, knowing that a given proportion of the population reports difficulties walking does not assist in planning what proportion could benefit from access to wheelchairs, surgeries, physiotherapy or more accessible buildings in their environment. Moreover, the translation of

questions is of paramount importance to ensure that item meaning is adequately transposed across data collection activities.

1.5.3 Objectively measured impairments in body function or structure

A different approach is to objectively measure the *body function or structure* component of the ICF, for example measuring visual acuity to determine the presence and level of visual impairment. This is the approach that has been used in a number of epidemiological surveys for assessing prevalence of vision, hearing and musculoskeletal impairment that have been developed by researchers at the London School of Hygiene & Tropical Medicine and elsewhere [77-79]. Advantages of this approach include the generation of standardised, reliable, objective data which can be used to inform health and rehabilitative service policies and programmes. For example, determining the magnitude, severity and cause of visual impairment to plan vision services such as how many people could benefit from refractive error services. These data are likely to be particularly important in low resourced settings, where coverage of such services is lower, and unmet need consequently higher[80, 81]. Further, some argue that it may produce more reliable and comparable data than through subjective self-report[68].

A criticism of this approach, however, is that impairment data in isolation are not a proxy for disability as they do not capture the individual's functioning at the activity and participation levels and therefore cannot inform on the overall experience of disability. Referring to the example used above, two individuals with the same level of visual impairment caused by refractive error may experience very different levels of activity limitations or participation restrictions depending on whether or not they have access to corrective glasses or Braille text books, and whether they live in accommodating environments or not. This in turn may lead to different lived experiences of disability despite the same level of visual impairment. However, there is limited available data on the relationship between measures of impairment, activity limitations and participation restrictions. This is needed to assess the relative merit of incorporating impairment data into ICF-compatible population-based surveys of disability.

A second caveat of previous population surveys using this clinical impairment approach is that surveys have typically been conducted focussing on one impairment group only (e.g. vision or hearing) and therefore data on the epidemiology of multiple impairments, are lacking. Finally, assessment of clinical impairments within surveys has previously depended on expensive specialist equipment and clinical professionals (many cadres of which are in limited supply in LMICs)[82]. This creates a comparative cost and time burden that makes such methods less suitable for census/national surveys in comparison with short, self-reported question sets on reported limitations that can be administered by trained interviewers.

1.5.4 Participation Restrictions

A fourth approach, is to estimate the *participation restrictions* component of the ICF. For example, to estimate whether respondents experience difficulties participating in major life areas such as accessing and completing education, work and employment, and engaging in community or social activities, as the result of the interaction between their health condition and contextual factors [21]. For example, the participation matrix developed for the SINTEF Living Conditions amongst Persons with disabilities Studies (see Box 4, next page), asks the participant to report their level of difficulty with completing specific tasks in their daily environment, inclusive of support from assistive devices or persons[83].

This approach is most frequently combined with tools measuring either body function/structure impairments or activity limitations, which are first used to define the sub-population identified as persons with disabilities. Few validated participation restriction tools exist, but relevant, standardised modules on access to/experience of education, work and employment etc. are included in numerous large-scale population-based surveys such as the Demographic and Health Surveys, World Health Survey and the Living Standards Measurements Study.

PARTICIPATION RESTRICTION

2. Do you have any difficulty performing this activity in your current environment?
[Current environment where you live, work and play etc for the majority of your time, and with the use of any assistive devices, either technical or personal]

Read out the options

PARTICIPATION RESTRICTION ITEMS*	SCORE
a. washing oneself	☐
b. care of body parts, teeth, nails and hair	☐
c. toileting	☐
d. dressing and undressing	☐
e. eating and drinking	☐
f. shopping (getting goods and services)	☐
g. preparing meals (cooking)	☐
h. doing housework (washing/cleaning)	☐
i. taking care of personal objects (mending/repairing)	☐
j. taking care of others	☐
k. making friends and maintaining friendships	☐
l. interacting with persons in authority (officials, village chiefs)	☐
m. interacting with strangers	☐
n. creating and maintaining family relationships	☐
o. making and maintaining intimate relationships	☐
p. going to school and studying (education)	☐
q. getting and keeping a job (work & employment)	☐
r. handling income and payments (economic life)	☐
s. clubs/organisations (community life)	☐
t. recreation/leisure (sports/play/crafts/hobbies/arts/culture)	☐
w. religious/spiritual activities	☐
x. political life and citizenship	☐

Coding:
0 = No problem
1 = Mild problem
2 = Moderate problem
3 = Severe problem
4 = Complete problem (unable to perform)
9 = Not specified /Not applicable

Box 4: SINTEF Participation Restriction Matrix

1.5.5 Contextual Factors

Central to the ICF definition of disability is the interaction between the individual's health condition and the *contextual factors* that lead to dysfunctioning at the body function or structure, activity or participation levels. These include environmental factors (the physical, social and attitudinal environment in which people live) and

personal factors (such as age, gender, background and resilience). Collection of data on contextual factors is therefore crucial for understanding the lived experience of disability and to identify mediators of dysfunctioning. For example, understanding how particular environmental factors relating to the physical, social or attitudinal scenarios (such as lack of accessible infrastructure, or stigmatising attitudes of others) diminish or increase functional limitations or participation restrictions. Secondly, to investigate how (or whether) the level of dysfunctioning is influenced by personal factors such as age, gender, ethnic group, socio-economic-status or previous education.

1.6 The need for a comprehensive disability measurement methodology

Different approaches to measuring disability will identify different sub-populations, resulting in non-comparable prevalence estimates. For example, consider two population-based surveys conducted in Uganda in 2006 – a Demographic and Health Survey (DHS) and the Ugandan National Household Survey (UNHS). The DHS estimated disability prevalence using the Washington Group Short Set, and the UNHS estimated disability prevalence using a single question (see Box 1). The DHS prevalence estimate (ages five and above) was 20%, whilst the UNHS estimate (all ages) was substantially lower, at 7% [84, 85].

The most appropriate measurement methodologies for assessing disability at the population-level necessarily relate to the objectives of the measurement exercise [86]. Mont et al. (2007) identify three major purposes for collecting data on disability: 1) designing appropriate services 2) monitoring the level of functioning in a population, and 3) assessing equalisation of opportunity for people with disabilities [68, 76].

Table 3 maps these purposes to the components of the ICF, and gives examples of how these data have been collected previously. As discussed above, prior data collection efforts have tended to focus on these objectives separately, using non comparable tools and methods to assess one component of the ICF only. However, it can be argued that these purposes, and collection of data across the different

components of the ICF, need not exist in isolation. A comprehensive approach to measuring disability in population-based surveys could incorporate sufficient elements of the different components of disability to collect data across the different key objectives.

Table 3: Elements of the ICF and objectives of data collection

Component of ICF	Perspective	Rationale for Data Collection	Example of Tool
Impairments in body function or structure	Body	Inform health and rehabilitative services with respect to aetiology and service needs of population	Rapid Assessment of Avoidable Blindness (RAAB) [87] Example Protocol: Measurement of Visual Acuity using Snellen Chart and ocular examination to determine cause of vision loss
Activity Limitations	Individual	Monitoring functioning in the population	Washington Group Short Set [71] Example Question: Do you have difficulty hearing, even if wearing a hearing aid? Response options: No difficulty, some difficulty, a lot of difficulty, cannot do at all
Participation Restriction	Society	Assessing equalisation of opportunities	SINTEF Living Standards Surveys[88] Example Question: Do you have difficulty washing yourself in your current environment? Response options: No problem, mild problem, moderate problem, severe problem or complete problem
Contextual Factors	Overall	Identifying mediators of dysfunctioning across all perspectives	Malawi Demographic and Health Survey 2016[89] Example Protocol: Household Roster of age, sex, previous education and marital status of respondents

As summarised above, there are pros and cons of identifying persons with disabilities in population-based surveys using either objective impairment or reported functional limitation tools. However, there is currently limited understanding about the extent to which measuring disability with these different

approaches and components of the ICF inter-relate. For example, do tools which seek to objectively measure impairments and tools which identify reported functional limitations identify the same, or similar sub-populations and, if not, how do they differ? Do the individuals identified by each type of tool experience similar levels of participation restrictions in comparison to one another, and in comparison to people who are not identified by these tools?

A small number of studies of the agreement between self-reported functional limitations and objective impairment in body function/structure criteria have been carried out amongst specific sub-populations or in regard to specific functional limitations, mostly in high income settings. For example, Kempen et al. (1996) found that there were discrepancies between self-reported and performance-based motor and sensory limitations amongst an elderly sample in the Netherlands, and that these were explained by socio-demographic factors and personality traits[90]. Similarly, a UK-based study of adults aged 48 – 92 by Yip et al. (2014) found that 36.2% of those determined to have low vision based on WHO visual acuity classifications reported "*good*", "*very good*" or "*excellent*" vision[91]. However, comprehensive surveys of disability that assess objectively measured impairments, reported functional limitations and participation restrictions simultaneously are currently lacking. This limits our understanding of how these approaches inter-relate within the context of the ICF, and how best to collect data on disability in population-based surveys.

Moreover, whilst previous surveys have analysed the association between disability (measured in numerous ways) and aspects of participation restriction – for example the association between disability and education, or livelihoods, no prior surveys to our knowledge have attempted this using a comprehensive methodology that incorporates both objective impairment and self-reported functional limitation tools. This is important to assess the effectiveness of either approach in identifying persons with disabilities across the three understood levels of dysfunctioning that make up the lived experience of disability.

Finally, analysis of the contextual factors (both environmental and personal) that affect the lived experience of disability is also imperative in the development of a

comprehensive disability survey methodology, to be able to identify associations that can potentially mediate the interaction between the person's health condition and their lived experience of disability.

Chapter Two: Statement of Research Question

2.1 Rationale of the Study

Development of a comprehensive and comparable disability measurement methodology compatible with the ICF is identified by the WHO World Report on Disability (2011) as crucial for informing country-level disability statistics, appropriate service planning and evidence-based advocacy for persons with disabilities globally[2]. One rationale for this is that robust data on prevalence of disability are lacking in many LMICs.

Previous population-based studies of disability – or components of disability – in LMICs have focused on either self-reported functional limitations or objectively evaluated impairments in body function or structure. There is consequently little clarity on how the measurement of these concepts inter-relate and the characteristics of the sub-population identified using either approach.

This study will contribute evidence on the inter-relationship between impairments and self-reported functional limitations, particularly in relation to participation restrictions, and inform on the most appropriate and comprehensive tools available to guide future surveys that are compatible with the ICF. To the best of the author's knowledge at the outset of this research, no prior surveys had attempted to measure these concepts simultaneously, or to quantify the relationship between them, as mediated by contextual factors.

In the context of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and monitoring the full and meaningful inclusion of persons with disabilities on an equal basis with others, accurately identifying persons with disabilities and assessing their lived experience of disability is imperative. For example, collecting data on access to and experience of education, livelihoods, and health, in comparison to people without disabilities. Currently, there are relatively limited data assessing this across different settings, particularly data that considers the contextual factors that mediate the lived experience amongst persons with disabilities.

Furthermore, the study will provide robust estimates of disability prevalence and data on access to services by people with disability in the two study countries (India and Cameroon), in order to help guide policy and programmes in these settings.

2.2 Study Aim

To develop a comprehensive population-based survey methodology for disability and to explore the inter-relationship between tools measuring different components of disability in two population-based surveys. Secondly, to use this data to assess the i) prevalence and ii) lived experience of disability, including predictors of inclusion amongst persons with disabilities.

2.3 Study Objectives

1. To identify and review existing tools for the measurement of disability in population-based surveys compatible with the ICF (*Chapter Three*)
2. To develop a population-based disability survey methodology that assesses the prevalence of impairment and self-reported functional limitations, and to undertake this survey in one district each of two countries (India and Cameroon). (*Chapters Four and Five*)
3. To assess the prevalence of disability and explore the relationship between measures of objectively-measured impairment and self-reported functional limitations (*Chapters Six, Seven and Eight*)
4. To assess the lived experience of disability and whether persons with disabilities have equal opportunities in their societies. (*Chapters Nine to Eleven*)
5. To identify predictors of access to health, education and employment among persons with disabilities (*Chapters Nine to Eleven*)

Chapter Three: Literature Review of ICF-compatible tools to measure components of disability in population-based surveys, with a focus on LMICs

3.1 Introduction

As explored in Section 1.5, a range of different tools and approaches to measuring disability in population-based surveys exist, most of which focus on specific components of the ICF framework.

This Chapter identifies and critically reviews ICF-compatible tools for the measurement of disability in population-based surveys (Research Study Objective 1). The review is scoping in nature, including tools identified from grey literature and expert recommendation.

3.2 Methods undertaken to complete the literature review

Medline, Embase and PsychInfo were searched for any studies of disability. In addition, the World Report on Disability and the World Health Organisation Disability Survey Repository were mined for references[2, 92]. Finally, experts participating in the Steering Group for this project were approached for their feedback and recommendations.

The original intention for this review was to separate it into tools measuring 1) impairments in body function or structure, 2) activity limitations and 3) participation restrictions, aligning with the three levels of dysfunctioning categorised in the ICF framework. However, this categorisation proved unfeasible, given both the design of many identified tools, and complexities in ICF high-level sub-categorisation of domains.

For example, the ICF separates "*body functions and structures*" into the extensive list of high-level sub-categories listed in Table 4. Similarly, high-level categories under the combined heading of "*Activities and Participation*" are shown in Table 5. As outlined in Section 1.5.2, the majority of self-reported functional limitation tools combine items of both body functions (e.g. seeing) and activities (e.g. mobility), crossing ICF high-level categories. In addition, a number of tools also include items relating to participation restriction (e.g. getting along with others, included in WHODAS 2.0).

Table 4: ICF Body Function and Structure High-Level Categories			
Body Functions		**Body Structures**	
B1	Mental functions	S1	Structures of the nervous system
B2	Sensory functions and pain	S2	The eye, ear and related structures
B3	Voice and speech functions	S3	Structures involved in voice and speech
B4	Functions of the cardiovascular, haematological, immunological and	S4	Structures of the cardiovascular, immunological and respiratory systems
B5	respiratory systems	S5	Structures related to the digestive, metabolic and endocrine systems
B6	Functions of the digestive, metabolic and endocrine systems	S6	Structures related to the genitourinary and reproductive systems
B7	Genitourinary and reproductive functions	S7	Structures related to movement
B8	Neuromusculoskeletal and movement-related functions	S8	Skin and related structures
	Functions of the skin and related structures		

Table 5: ICF High Level Activities and Participation Domains	
Activities and Participation	
D1	Learning and Applying Knowledge
D2	General Tasks and demands
D3	Communications
D4	Mobility
D5	Self-Care
D6	Domestic Life
D7	Interpersonal Interactions and Relationships
D8	Major Life Areas
D9	Community, social and civil life

The combination of activities and participation domains into one category in the ICF adds further complexity to disaggregation between the two. Eyssen et al. (2011) suggest differentiation between D1 – D3 (Table 5) as related to activities only, D4 – D5 as combining activities and participation, and D6 – D9 as referring to participation only [93].

Because of these complexities, tools were reviewed across the following three categories: objective measurements of impairment in body function and structure (Section 3.2), tools to measure reported limitations in body function or activities (combined as "*functional limitations*") (Section 3.3), and tools to predominantly

measure participation (Section 3.4). When a tool incorporates items across these sub-sections, this is clearly stated and the tool is described in detail in the section related to the majority of its items.

Critical reflection on the use of each tool in a population-based survey methodology included a combination of prior use and validation of the tool in LMIC settings, alongside ease and cost of use. Tools for inclusion in the population-based surveys in Cameroon and India were selected based on this review.

3.3 Review of tools to objectively measure impairments in body functions and structures

This review includes tools developed for the assessment of prevalence and severity of impairments in population-based surveys. Where relevant and included, details of assessment of aetiology are also described.

Table 4 in Section 3.1 above provided the high-level ICF categories for body function and structure. Within each sub-category (allocated its own chapter in the ICF), cascading sub-chapters lead to specific descriptions of each domain of functioning, providing a comprehensive framework of classifications of functioning at the level of the body [18]. Collection of objective data against each of these sub-categories would not be feasible within the scope of a population-based study. Many definitions, for example b43500 on "*the body's response of sensitizations to a specific foreign substance*", would require complex, invasive clinical testing, whilst others such as b5103 "*Manipulation of food in the mouth*" are likely to identify relatively small sub-populations at considerable cost. Thus, in the context of feasibility in population-based surveys in LMICs, tools to objectively assess impairments in body function and structure domains included in this review include the areas expressly stipulated in the UNCRPD definition of disability: long-term physical, mental, intellectual or sensory impairments.

3.3.1 Physical Impairments

Physical, or musculoskeletal impairment (MSI), represents a large range of different conditions and disorders that can manifest in a wide array of functional limitations. However, few studies of MSI have been undertaken in LMICs, in part due to a lack of agreement on case definitions and appropriate methodologies [38].

A number of tools have been developed to objectively assess physical functioning within the rehabilitation sector. These include the Physical Performance Test, originally designed to assess degrees of difficulty in multiple domains of physical functioning amongst older people, and the 6 Minute Walk Test, which measures distance ambulated and has been widely validated as a test of aerobic capacity and endurance in the rehabilitation of patients post stroke, spinal cord injury and amputation [94, 95]. Whilst both tools can be administered by non-clinical personnel, neither provide information on aetiology to inform service planning, nor have been validated in LMICs.

In the absence of validated tools for the estimation of MSI prevalence in LMICs, the Rapid Assessment of Musculoskeletal Impairment (RAM) was developed in 2008 [96]. The RAM is a two-stage tool comprising seven screening questions on reported functional limitations, observation of activities and a standardised examination by a physiotherapist or other clinician [97]. The tool is appropriate for all ages. The RAM also includes screening for seizures, given their association with other physical impairments including burn-related injury and cerebral palsy. In addition, substantial stigma related to epilepsy has previously been reported by a number of studies[98]. The screening tool was first validated in Malawi, where it was shown to have sensitivity of 97.8% and specificity of 98.8%. Subsequently it was pilot tested and used to conduct a large scale national population-based survey on MSI in Rwanda[96].

3.3.2 Sensory Impairments

Tools and methodologies to estimate the prevalence of sensory impairments (i.e. in vision or hearing) are more widely available in the literature.

Vision

Several large-scale surveys of visual impairment and blindness, incorporating data on prevalence, severity and aetiology, have previously been undertaken in LMICs. These include National Surveys of Visual Impairment and Blindness in Nigeria (adults aged 40 and above), Pakistan and Bangladesh (both adults 30 and above) [99-101]. In each, the primary methodology for determining visual impairment was Visual Acuity (VA) testing, using portable logMar 'E-charts' administered by ophthalmic nurses [102]. Classification of no, early, moderate, severe or profound (blind) visual impairment is based on the participant's VA in the better eye. Assessments of vision and cause of vision loss were conducted by a team of ophthalmic nurses, optometrists and ophthalmologists. Tests included auto refraction, keratometry, and visual field screen; eye examination, slit lamp examination and lens grading respectively, dependent on the participants' pathway through the examination protocol[100, 101, 103]. These methods provide detailed information on level and causes of vision loss, but require sophisticated equipment and lengthy examinations by ophthalmologists and other clinicians, making them costly, time-consuming and resource intensive to conduct.

An alternative approach is the Rapid Assessment of Avoidable Blindness (RAAB). This is a robust survey methodology for the estimation of visual impairment and blindness, which has been conducted to date in more than 200 surveys, across more than 20 LMICs [77, 87, 104, 105]. The RAAB method uses a simplified E-chart to assess vision (see Photo 1). For people identified to have vision impairment, a simplified ocular examination is undertaken to determine the cause of vision loss. Vision testing can be completed without any clinical experience, but an ophthalmologist or ophthalmic clinical officer is required to conduct the examination and determine the cause of vision loss.

Photo 1: Tumbling E Chart RAAB

The RAAB was developed to assess prevalence and causes of blindness in adults aged fifty and above. This is because of both the high proportion of blindness in this age group and evidenced similarity in distribution of causes compared to the all-age population, allowing extrapolation to the total population[77]. However, the examination procedures used are suitable for all adults and older children, and the simplified techniques involved ensure that RAAB is rapid and affordable.

Separate methods are needed for visual acuity screening in young children. The WHO Prevention of Blindness Programme (WHO/PBL) Eye Examination Record for Children with Blindness and Low Vision is a standardised form for the assessment of visual loss in children that continues to be the best-practice tool for the assessment and diagnosis of visual impairment in this age group in LMICs [106]. The form collects data on presenting and pinhole visual acuity, previous eye surgery, site of abnormality affecting vision loss, prognosis, education and referral needed. Very young children (approximately 0 to 3 years) or children with cognitive or communication limitations may be unable to respond to acuity test instructions. In this case, Chandna and Gilbert (2010) recommend a combination of parental report and basic diagnostic assessment of the child's ability to fix and follow toys, lights or their caregiver as he or she moves around the room[107].

Hearing

The WHO Ear and Hearing Disorders Survey Protocol (1999) provides a standard approach to investigation of hearing impairment and deafness[78]. A systematic review of cross-sectional epidemiological studies of hearing impairment in 2008 determined that the protocol had been used in a national population-based study of hearing impairment in Oman (1997), and regional/provincial studies in Brazil (2003), China (2006), India (1997), Indonesia (1998), Myanmar (2001), Nigeria (2000), Sri Lanka (2001) and Vietnam (2001) [108].

The WHO Ear and Hearing Disorders Protocol provides a two-stage methodology whereby all participants are screened to assess their presenting decibel hearing level (dbHL), and those determined to experience any level of hearing loss are examined by an Ear Nose and Throat (ENT) professional for cause. DbHL is

measured using Pure Tone Audiometry (PTA) assessed using a Field Audiometer, which does not require clinical expertise. Noise-cancelling headphones are worn by the participant, who raises a hand to indicate hearing a noise emitted in each ear separately at a range of levels and frequencies[78]. PTA readings are used to establish an average level of decibel hearing level (dbHL) loss, categorised as mild, moderate, severe and profound (deaf) based on the hearing in the better ear. Children below the age of four years, for whom PTA is not feasible (as a response is required), are assessed using a short behavioural observation screen. Additional recommended tests – included in an update to the Ear and Hearing Disorders Examination Form in 2009 – include Oto-Acoustic Emission (OAE) testing, Auditory Brainstem Response (ABR) and Tympanometry[109]. OAE provides pass/fail data on functioning of the inner ear, whilst ABR measures high-frequency hearing and Tympanometry measures the function of the middle ear, and the presence or not of otitis media with effusion [110]. Each of these tests requires costly equipment, and the latter two require clinical interpretation of results.

While PTA is the gold standard measure of hearing loss and severity, it is lengthy (up to 40 minutes per participant). Therefore, whilst it is recommended that where feasible, PTA is undertaken by all participants capable of responding to test instructions, a two-stage methodology, including screen by Oto-Acoustic Emission or shortened PTA testing, is considered acceptable by authors of the WHO Protocol in the context of population-based surveys[111].

3.3.3 Mental Function (including intellectual) Impairments

Mental Functions in the ICF cover a broad range of areas including intellectual functioning, psychosocial functioning, emotion, energy and drive[112]. This review focuses primarily on intellectual and psychosocial functioning, in accordance with the UNCRPD.

Many tools, in particular condition-specific tools, have been developed for psychosocial screening in high income health-facility settings. However relatively few have been developed for, or validated in, LMICs. A recent systematic review of validated screening tools for common mental disorders (CMDs) in LMICs (2016)

identified the Self-Reported Questionnaire (SRQ-20), General Health Questionnaire (GHQ-12), Hospital Anxiety and Depression Questionnaire (HADS-D) and Patient Health Questionnaire (PHQ-9, for depressive disorders only) as having performed best in comparison to a gold standard across studies in LMICs identified in the review[113]. Each of these tools relies on participant response (self- or interviewer administered) to a list of items related to symptoms of general or specific Common Mental Disorders with either binomial or rating-scale response[114, 115]. However, the review authors caution on the need to pilot test the use of any screening tool in a new context, to ensure cultural relevance and appropriate translation.

Intellectual functioning is defined as a sub-chapter of mental functioning in the ICF, namely *"General mental functions, required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the life span"* [112]. Screening tools to address dementia – age-related neurodegeneration of mental functioning – are relatively common. For example, the Community Screening Instrument for Dementia (CSI-D) has been validated in many LMICs, and uses a combination of cognitive function testing and general function reporting to determine an overall participant score against a predictive algorithm[116]. Several broader screening tools for intellectual impairments more generally were identified in the literature, including the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) and Diagnostic Assessment for the Severely Handicapped (DASH)[117]. However, there is no available evidence of these tools being adapted for, or used in LMICs. Moreover, recognised limitations in the use of screening tools for intellectual impairment include the lack of an agreed international procedure for Intelligence Quotient (IQ) measurement, and that the aetiology of intellectual impairments cannot be identified in 30 – 50% of cases even following thorough diagnostic evaluation[117, 118].

3.3.4 Tools selected for inclusion in the population-based surveys

Considering the need for tools to be standardised and reasonably rapid, and to be appropriate for use in LMICs, we selected the following impairment tools for use in the comprehensive disability survey method:

The RAAB (vision), WHO Ear and Hearing Survey Protocol (hearing) and RAM (physical impairment and epilepsy) are standardised tools that have been developed specifically for use in LMICs. They rely on clinical expertise but use relatively simplified methods that make them suitable and affordable for use in population-based surveys in the two research settings. Given that the RAM collects data on seizures, and that seizures are not included in reported functional limitation tools, this element of the tool was retained. This is in contrast to the potentially disabling functional limitations related to other health conditions such as HIV (for example, difficulties with vision or hearing) which are captured in both the self-reported tools and via other clinical tools incorporated into the study. Despite the exclusion of seizures from reported functioning tools, previous research has shown an association both between epilepsy and lower health-related quality of life, stigma and exclusion, and between accidents during seizures and long term physical impairment[119, 120].

Of the shortlist of recommended tools for mental health disorders, the PHQ-9 was selected based on its prior use in both study settings (India and Cameroon)[121, 122]. Unfortunately, no appropriate tools for intellectual impairment were identified.

Lastly, the statement that all clinical tools used within this study are "objective" deserves to be critically scrutinised. Whilst most of the clinical tools rely predominantly on observed, latent characteristics (i.e. capacity to hear or see as measured objectively,) assessed in a standardised way, an element of self-report and clinician judgement, exists particularly in the tools used to measure MSI and clinical depression. The term 'objective' applied to the clinical tools is used in this thesis to delineate between an emphasis on self-report (as in the functional tools described in the next section) and an emphasis on standardised observation,

3.4 Review of tools to measure reported functional limitations

A review of the literature was undertaken to identify self-reported measures of functional limitations. Functional limitations within the ICF are defined as

limitations in either body function/structure or activities [20]. The aim of the review was therefore to identify self-reported measures of body function/structure or activity limitation that have been used in, or developed for, population-based surveys in LMICs.

Eligible tools identified were:

Adults:

- The ICF Checklist [123]
- The World Health Organisation Disability Assessment Schedule (WHODAS 2.0) Short and Extended sets [124]
- The Washington Group Short and Extended Sets on Functioning [72]
- The Rapid Assessment of Disability (RAD) [125]
- The Model Disability Survey (MDS) [126]
- The Disability Screening Questionnaire (DSQ34) [127]

Children:

- The Washington Group/UNICEF Child Functioning Module [128]
- The Ten Questions (TQ) tool [129]
- WHODAS Child [130]
- RAD child [125]

Summary Tables 6 and 7 provide the body function/structure and activity limitation domains included in each tool identified, based on their high-level domain categorisation within the ICF. As many tools also included domains related to participation, these are also listed when applicable. Table 8 provides an overview of population covered, item quantity, response options and criteria for determining presence of disability for prevalence estimates for all tools included in the review.

The ICF Checklist

The ICF checklist was developed by the WHO following the formal endorsement of the ICF into the WHO Family of Classifications, as a tool predominantly for clinicians in health-care settings [131]. The checklist contains items on each domain in the ICF related to body function and structure, activity, participation and the environment, and qualifiers of both the individual's capacity (what they are able to do in a "*standardised*" environment[4]) and performance (what they are able to do in their current environment)[20]. Unlike other tools in this review which are entirely self-report, the ICF Checklist incorporates both self-report and clinical observation of limitation in function, and is completed by the clinician [123]. Whilst the ICF Checklist is perhaps the most comprehensive in terms of the ICF, it contains over ninety items, posing a feasibility challenge in population-based survey settings. Moreover, a 2010 systematic review of literature on use of the ICF did not identify any articles reporting either the development or validation of the ICF checklist, or recommended thresholds to ascertain disability prevalence[132].

Since that review was completed, Cockburn et al. (2014) report using the ICF Checklist in a population-based survey in North West Cameroon [133]. However, the study included a single question asked to a household informant ("*Is there anyone in the house who has any form of disability or handicap?*") to determine whether or not to complete the Checklist. Using such binary questions to screen carries limitations as discussed in Section 1.5.1. In addition, the study team reported substantial data collection difficulties both in rating the performance and capacity qualifiers, and in recording negative and positive environmental factors.

The WHODAS 2.0

The WHO Disability Assessment Scale (WHODAS) is an ICF-compatible update of the 1988 WHO Psychiatric Disability Assessment Schedule[134]. WHODAS 2.0 includes both short (12 item) and extended (36 item) question sets for adults (18+) [124,

[4] Defined by the authors as one that neutralises the varying impact of different environments to allow for cross-context comparison

130]. The WHODAS Child is described below. The adult questionnaire focuses on self-reported limitation across six activity and participation categories – cognition, mobility, self-care, getting along, life activities and participation – and uses a five-point scale of reported difficulty ("*none*", "*mild*", "*moderate*", "*severe*" and "*extreme*") to measure limitation, alongside an overall estimate of days affected by the condition [70].

WHODAS 2.0 was developed in 2010 following extensive consultation and review of available tools, and was tested for cross-cultural applicability and psychometric reliability using classical item response theory (IRT) [135]. Overall and domain-specific summary scores can be derived either by simple summation of responses (coded per item between "*none*"=0 and "*extreme*"=5) or by using a freely available IRT algorithm from the WHO that generates overall and domain-specific scores on a metric between 0 ("*no disability*") and 100 ("*full disability*"), weighted by item and severity[135]. No criteria for determining a cut off for disability prevalence is provided, although data on population norms are available for comparison to survey data[70].

A modified version of WHODAS 2.0 was used in the WHO World Mental Health Surveys across 16 countries between 2001 and 2004, and the tool has been validated as a functional assessment measure in studies on specific health conditions including back pain, depression and hearing loss [70, 136]. The WHODAS 2.0 was developed for use in both clinical and population-based settings and is shorter, quicker and simpler to administer than the ICF checklist [124]. However, sensory limitations (limitations in seeing or hearing) are not included in the tool, potentially creating downward bias in prevalence estimates.

The Washington Group Short and Extended Sets on Functioning

The Washington Group on Disability Statistics (WG) was established in 2001 as a United Nations Statistical Commission City Group, tasked with the development of standard principles and measures for disability data collection in national Censuses [72]. The WG first developed the short set on functioning (SS-F), which consists of six questions concerning reported functional limitations in the domains of seeing,

hearing, walking/climbing steps, remembering/concentrating, self-care and communicating/understanding, with response options of "*no difficulties*", "*some difficulty*", "*a lot of difficulty*" or "*cannot do*" [71].

The SS-F is appropriate for the population aged 5 and above, and is a rapid and simple tool, developed to maximise the data on disability that can be collected in Census settings – i.e. within tight time and resource constraints[72]. The SS-F has since been recommended for use in the 2020 round of population and housing censuses by the United Nations Statistics Division, and has been used widely in LMICs[137]. An advantage of the use of the SS-F is the recommended clear threshold for determining the population prevalence of disability, or disaggregation of data by disability. This allows a field categorisation of persons with and without disabilities that does not require analytics, and can be useful to estimate whether people with disabilities experience equal opportunities in their societies. This threshold is defined as any participant reporting "*any one domain a lot of difficulty or cannot do*" [83, 137-141]. Unlike the WHODAS 2.0, the SS-F focuses on functional limitations only, rather than functional limitations and participation restrictions. It includes hearing function, which is excluded in WHODAS 2.0, but does not incorporate domains related to psychosocial function.

More recently, the WG developed an Extended Set on Functioning (ES-F) for use in population-based surveys. The ES-F comprises additional items for several of the six domains of the short set, including near and far vision, hearing in loud and quiet environments, and short and long distance mobility limitations[142]. It also contains additional body function and activity domains in relation to upper body (strength and dexterity), affect (anxiety and depression) and generalised symptoms (pain and fatigue)[72]. Responses are categorised as in the short set except for anxiety, depression, pain and fatigue. For these, participants report first frequency of symptoms (anxiety/depression: "*daily*", "*weekly*", "*monthly*", "*a few times a year*", "*never*"; pain/fatigue: "*never*", "*some days*", "*most days*", "*every day*") and for those who experience symptoms, a follow-up question on intensity of feelings ("*a little*", "*a lot*", "*somewhere between a little and a lot*") is included.

The purpose of the ES-F is to provide more comprehensive data on functioning where resources allow, such as in disability-focused or other population-based surveys [71, 143]. Both the SS-F and ES-F have undergone substantial cognitive testing using qualitative methodologies and software developed by the Questionnaire Design Research Laboratory at the National Center for Health Statistics, but quantitative psychometric property testing is lacking [72, 144]. The WG have previously stated that the appropriate threshold for estimating disability prevalence using the WG ES-F is related to the purpose of the data collection activity [141]. Final threshold recommendations for estimating disability prevalence using the ES-F have thus not yet been published. However, draft proposed recommendations for analysis of the ES-F were shared at the Washington Group Annual Meeting in South Africa, November 2016 [145]. The proposal was equivalent to reporting "*a lot*" or greater difficulty in any domain of the short set, reporting "*a lot*" or greater difficulty in domains of the upper body, or reporting "*daily*" and "*a lot*" for the frequency and intensity questions related to anxiety or depression respectively.

The Rapid Assessment of Disability (RAD)

The Rapid Assessment of Disability (RAD) is a complete survey methodology which consists of a household questionnaire and individual questionnaire for adults. The RAD was developed by the Nossal Institute at the University of Melbourne, Australia, to measure progress towards inclusion of persons with disabilities in their societies as per the UNCRPD[146]. The assessment of disability utilises questions drawn from several of the above mentioned tools, including the WG SS-F, the WHODAS 2.0, and the ICF Checklist [125]. Continuum of functioning in RAD is expressed in terms of how often the person experiences limitation related to specific domains, rather than intensity of limitation. For example, participants are asked first a binary yes/no "*do you have any difficulty seeing, even if wearing glasses*"; amongst those who report affirmatively they are then asked "how often" with the response categories "*some*" "*most*" or "*all of*" the time[146]. Disability prevalence is categorised as reporting difficulty "*most*" or "*all*" of the time for any one item related to physical, sensory or cognitive domains, or at least two items across psychological distress domains[147].

Alongside collection of socio-demographic data, additional modules of the RAD include access to and participation in the community, and quality of life. The RAD methodology thus collects data on both functional limitations and participation restrictions. However, the complete adult interviews were determined in field-testing to take up to 45 minutes per person and is therefore relatively time-consuming. Moreover, the focus on frequency as opposed to intensity of limitations is non-comparable to other self-reported tools[147].

The Ten Questions (TQ) tool

For children, the Ten Questions tool has been the most widely used, adopted by twenty-six countries in the third round (2005-2008) of the UNICEF Multiple Indicator Cluster Survey (MICS) [148]. The module was designed to identify children aged 2-9 years at risk of disability. In this tool, parents are asked ten binary yes/no questions about difficulties their child experiences in the body function domains of intellectual impairment, developmental delay, physical impairment, vision, hearing and seizures [46]. For example "*Compared with other children, does or did (name) have any serious delay in sitting, standing, or walking*?" The tool is rapid and appropriate for use in low literacy populations[149]. However, despite high sensitivity the tool has shown very low specificity for specific impairments (particularly vision and hearing) and has not been validated for children above the age of nine [46, 149].

The Washington Group/UNICEF Child Functioning Module

Recently, the WG partnered with UNICEF to replace the Ten Questions tool with a more comprehensive module, the Extended Set on Functioning for Children (UNICEF/WG ES-F). This tool, which is designed to identify children at risk of disability aged 2 and above, contains both age-specific domains of functioning and age-appropriate question variations [148]. The UNICEF/WG ES-F reflects the additional domains incorporated in the ICF-CY, thus including seeing, hearing, walking, understanding, being understood, learning, controlling behaviour and playing[128]. Additional domains for children aged 5-17 only include self-care, remembering, feeling worried/sad, completing a task, accepting change and getting

along with other children. The UNICEF/WG ES-F is longer than the TQ and at the time of review a threshold for determining disability prevalence had not been established. However, its development in accordance with the ICF-CY and using the same structure as the WG ES-F suggests close compatibility with the ICF. The final module was launched in October 2016 (see Appendix 6) and a manual for its use and analysis is due for launch later in 2017[150].

The WHODAS Child

The WHODAS Child was developed by the Diagnostic and Statistical Manual of Mental Disorders (DSM) Version 5 Impairment/Disability workgroup in 2005[151]. The WHODAS Child has three versions – a parent reported version for children 0 to 17, a self-reported version for adolescents 12 and above, and a clinician's version. Following the structure of the WHODAS, items relate to understanding and communicating, getting around (mobility), self-care, getting along with people, life activities (school and non-school) and participating in society. Scores include an overall health rating ("*very good*", "*good*", "*moderate*", "*bad*" and "*very bad*") and reported difficulty ("*none*", "*mild*", "*moderate*", "*severe*", "*extreme/cannot do*") across 34 additional items, and no threshold for disability prevalence is provided. One validation study amongst a sample of children referred for psychosocial assessment in Rwanda in 2011 showed good agreement with clinician determined psychosocial disorder, but the tool is not publically available and there is no evidence of further validation or use of the tool in general child populations or in other settings[130].

The RAD child

The RAD child module is stated in the Rapid Assessment of Disability Toolkit (2013) as being under development and requiring further testing and analyses prior to being made available for use[125]. However, no further information was identified in the literature on the development, content or field testing of the module to include in this review.

Since this research was undertaken, two further tools to measure self-reported functional limitations used in, or developed for, population-based surveys in LMICs

– The Model Disability Survey (MDS) and the Disability Screening Questionnaire (DSQ34) – have been developed and pilot-tested.

The Model Disability Survey (MDS)

The MDS is a joint initiative of the WHO and the World Bank. This approach emphasises the continuum of functioning experienced by everyone in the population as a result of the interaction between their health condition, and contextual (environmental and personal) factors [126]. The MDS disaggregates data collection to incorporate both activity limitations as a result of a health condition (capacity), and the individual's experienced limitations in functioning (performance), so as to determine metric capacity and performance scales. Disability status is defined *a posteriori* at the analysis phase, based on the distribution of the data [126]. In addition, the MDS provides a standardised child-specific module, and modules on work history and benefits, environmental factors, health-care utilisations, and satisfaction and wellbeing. This approach is still under development. However from a pragmatic perspective, the *a posteriori* classification may limit opportunities for collecting in-depth data on the lived experience of disability using case-control methodologies. For example, such data must be collected for all participants using the MDS, who are categorised as persons with or without disabilities at the analysis phase, creating a potential burden on field methodologies.

The Disability Screening Questionnaire (DSQ34)

The DSQ was originally designed as a self-reported screening tool for a survey in Afghanistan (DSQ-27). It comprises domains related to activity limitations and specific body structure or function linked to impairment (e.g. paralysis, seizures) in the ICF[127]. The DSQ does not in itself incorporate a measure of participation, but the tool's authors recommend the additional use of a participation tool based on the capabilities approach[86].

3.4.1 Tools selected for inclusion in the population-based surveys

The review of the literature established a number of tools developed for, or used in population-based surveys of disability in LMICs. Validation techniques (qualitative or quantitative) were reported for most (WHODAS 2.0, Washington Group tools, RAD adult, Ten Questions) but not all (ICF checklist, RAD child) tools. Several tools provided recommendations for the estimation of disability prevalence in population-based surveys (The WG SS-F, the RAD adult and the TQ) but most did not.

The WG ES-F and UNICEF/WG ES-F were selected to assess self-reported functional limitations in the population-based surveys amongst adults and children respectively. Whilst the ICF checklist and RAD adult tools are more comprehensive, their length limits feasibility in population-based surveys. The WG SS-F, whilst rapid and including a clear prevalence threshold for disability, does not include domains of mental functioning. The WHODAS adult module, whilst well-validated, does not include either sensory domains or a clear threshold for estimating disability prevalence. The TQ has shown very limited sensitivity, and the RAD child is not available for review. The WHODAS child has also been tested only in very limited settings and is not available for general use. Therefore, despite not having pre-validated disability prevalence thresholds, the WG ES-F and UNICEF/WG ES-F were considered the pragmatic choice for inclusion in the population-based surveys given their range of items and length. In collaboration with the Washington Group and UNICEF, the present study contributed to the further testing and refinement of UNICEF/WG ES-F.

Table 6: Summary of reported functional limitation tools for adults													
Tool	**Body Functions**				**Activities**					**Participation**			
	Seeing	Hearing	Mental	Physical	Learning and applying	General Tasks	Communication	Mobility	Self-care	Domestic Life	Inter-personal	Major Life Areas	Community social and civic
WG SS													
WG E	X	X	a, b				X	X					
WHODAS 2.0 SS			a, c										
WHODAS 2.0 ES			a, c										
RAD	X	X	a, b, c				X	X					
ICF Checklist			a, b, c										
MDS			a, b										
DSQ-34			a,b,c										
Table 7: Summary of reported functional limitation tools for children													
	Seeing	Hearing	Mental	Physical	Learning and applying	General Tasks	Communication	Mobility	Self-care	Domestic Life	Inter-personal	Major Life Areas	Community social and civic
UNICEF/WG ES	X	X	a, b*, c			*			*		*		
TQ			a										
WHODAS child			a										

Table Key:
X – question first asks if person uses assistive device to maximise functioning, then (whilst using their device if they use one) what their functional status is
Mental Function sub-categories:
a – intellectual (e.g. remember, concentrate), b – psychosocial (e.g. anxiety, depression), c – emotion
* Ages 5 – 17 only

Table 8: Summary of items and disability prevalence thresholds in identified tools					
Tool Name	**Age Range**	**No. Items**	**ICF categories**	**Response options**	**Disability Prevalence threshold**
WG SS-F	5+	6	BF, A	No difficulty, some difficulty, a lot of difficulty, cannot do	Any one domain 'a lot of difficulty' or 'cannot do'
WG ES-F	18+	25 – 40	BF, A	No difficulty, some difficulty, a lot of difficulty, cannot do	Not provided
WHODAS 2.0 SS	18+	12	BF, A, P	No difficulty, mild difficulty, moderate difficulty, severe difficulty, extreme difficulty/cannot do	Not provided
WHODAS 2.0 ES	18+	36	BF, A, P	No difficulty, mild difficulty, moderate difficulty, severe difficulty, extreme difficulty/cannot do	Not provided
RAD	18+	16	BF, A, P	Do you have difficulty x (Y/N) If Yes: some of the time, most of the time, all of the time	Difficulty 'most' or 'all of the time' in at least one item from the physical/ sensory/ cognitive domains or at least two items from the psychological distress domain
ICF Checklist	18+	110	BF, A, P	Impairments: No impairment, mild impairment, moderate impairment, severe impairment, complete impairment Activities – Performance: No difficulty, mild difficulty, moderate difficulty, severe difficulty, complete difficulty Activities – Capacity: No difficulty, mild difficulty, moderate difficulty, severe difficulty, complete difficulty	Not provided
MDS	2+	44	BF, A, P	Capacity: No difficulty, mild difficulty, moderate difficulty, severe difficulty, extreme difficulty/cannot do	Determined *a posteriori* based on distribution of functioning across sample

				Performance: No problem, mild problem, moderate problem, severe problem, extreme problem/cannot do	
DSQ-34	15+	34	BF, A, P	Never, Sometimes, Often, Constantly/always	Mild disability: 'yes sometimes' to at least two questions Moderate disability: 'yes sometimes' to at least two questions Severe disability: 'yes, often' to at least one question but less than three questions Very severe disability: 'constantly/always' to at least one question or 'often' to three or more questions
UNICEF/ WG ES-F	2-17	14	BF, A, P	No difficulty, some difficulty, a lot of difficulty, cannot do	Not provided
TQ	2-9	10	BF, A	Yes/No	At least one item 'Yes'
WHODAS child	0 - 17	35	A, P	Overall health rating: very good, good, moderate, bad and very bad Activities/participation: No difficulty, mild difficulty, moderate difficulty, severe difficulty, extreme difficulty/cannot do	Not provided
BF = Body Functions, A = Activities, P = Participation					

3.5 Review of tools to measure participation restrictions

The ICF defines participation both as "*involvement in a life situation*" and "*the lived experience*" of disability in the actual context in which people live[21]. However, a number of recent literature reviews have critiqued the lack of clarity of this component of the ICF, and the limitations this poses on developing appropriate tools [93, 152, 153].

In particular, Whiteneck and Djikers (2009), Eyssen et al. (2011) and Pisker et al. (2014) all critique the lack of a comprehensive definition of participation, that adequately differentiates it as a concept from activities and environment, and is measurable in a uniform way [93, 152, 154]. Eyssen et al. (2011)'s review of the literature determined that tools developed to measure participation fall into three broad groupings: measures of participation accomplishment (for example, "*how often are you able to*.."), measures of participation problems ("*how difficult is it for you to*..") and measures of participation satisfaction ("*how satisfied do you feel with your ability to*.."). Notably, the latter concept of participation satisfaction – i.e. to what degree the person feels they are able to perform the social roles they identify with – is not incorporated in the ICF, an omission strongly critiqued in the literature[152].

Eyssen et al. (2011)'s criteria can be applied to the four tools identified in the previous section that incorporated participation items – the WHODAS 2.0, the ICF Checklist, the UNICEF/WG ESF and the RAD. Consequently, the WHODAS 2.0, ICF Checklist and UNICEF/WG ESF participation items correspond to measures of participation problems, whilst the RAD measures participation accomplishment.

A systematic, scoping review of measures of participation in disability and rehabilitation research was conducted by Seekins et al. in 2012 (2012)[153]. The authors identified 67 distinct instruments, only 9 of which had been used in more than one study and without reporting whether their use was in population-based surveys and/or in LMICs [153]. Of these, the two most commonly used tools (three studies each) were the Community Integration Questionnaire and the child-specific Paediatric Evaluation of Disability Inventory. Both tools were developed in high-

income settings, and there is no evidence of their use in population-based surveys in LMICs[155, 156].

In addition, an 18-item Participation Scale (P-Scale) was developed by Van Brakel et al. (2006) as a cross-culturally applicable tool based on the nine Activity and Participation domains of the ICF[157]. The tool (not identified by Seekins systematic review), which measures participation problems, was field-tested in Nepal, Brazil and India, and found to possess satisfactory validity, reliability and dynamicity across sites[157]. However, validation studies were limited to participants with leprosy, spinal cord injuries and polio, and further studies to determine validity amongst participants with other impairments, or with participants without disabilities as in a population-based survey, are lacking.

The "*Surveys on living conditions among people with activity limitations in developing countries"*, coordinated by SINTEF in collaboration with local partners and stakeholders, has covered ten countries in Africa and one in Asia to date[158, 159]. The survey methodology includes disability screening using the Washington Group Short Set, followed by in-depth questionnaires at the household and individual level for persons determined via the Short Set to have disabilities, alongside matched controls. Within the individual questionnaire, a participation module provides data on ability to complete core tasks (such as self-care or tasks of daily living) in line with the participation domains of the ICF [158]. This tool also uses the participation problem approach.

Finally, in addition to these scales or sets of questions, participation can be assessed through reported access to, and experience of, activities that an individual may value. For example, education, work, political and social events. The Washington Group, for example, are currently developing an education module, to estimate participation restrictions amongst children via their access to, and experience of, education. Moreover, standardised, cross-culturally applicable modules on access to and experience of livelihoods, education, health-care etc. can be found in large population-based surveys including the above mentioned Surveys on living Conditions, the USAID Demographic and Health Surveys or the World Bank Living Standards Measurement Study surveys[159-161] .

3.5.1 Tools selected for inclusion in the population-based surveys

The SINTEF Living Conditions Participation Module was selected for inclusion in the study based on its prior use in multiple LMICs, and its close correlation to the participation domains of the ICF[158]. In addition, we used standard modules on access to livelihoods, education and health care to explore the "*lived experience*" of disability in terms of participation as defined in the ICF.

Chapter Four: Developing a population-based disability survey methodology

4.1 Introduction

A comprehensive disability survey methodology was developed using measurement tools selected in the previous chapter and standard sampling approaches (Objective 2 of the research). This survey was undertaken in one district each of Cameroon (Fundong Health District, North West Cameroon 2013) and India (Mahabubnagar District, Telangana State 2014). This chapter first presents an overview of the survey method and the study settings, before describing the steps involved in more detail.

4.2 Overview of Survey Methods

The study comprised of two principle components:

1. A population-based survey to estimate the prevalence of disability

2. A nested case-control study to compare the lived experience of people with and without disabilities in terms of their socio-economic situation and their access to and experience of health and rehabilitation, livelihood opportunities, education, and participation.

4.2.1 Population-based Survey (see Section 4.4 for full details)

An all-age population-based survey, was undertaken in one district each of Cameroon (Fundong Health District, North West Region, 2013) and India (Mahabubnagar District, Telangana State[5], 2014). Survey participants were a) interviewed for self-reported functional limitations and b) screened for visual, hearing and musculoskeletal impairments, epilepsy and depression (aged 18+) using objective clinical tools.

[5] Telangana State was bifurcated from Andhra Pradesh State in June 2014, shortly after the data collection was completed

4.2.2 Nested case-control study (see Section 4.5 for full details)

All participants aged ≥5 years who either self-reported functional limitations, or were identified to have epilepsy, severe depression or a moderate or worse clinical impairment (**'cases'**) were invited to participate in a nested case-control study. For each case, one community, age and sex matched **control** not meeting case criteria (at both the individual and household level) was also selected.

Cases and controls undertook a structured interview incorporating modules on socio-demographics, socio-economic status, livelihoods, education, health, activities and participation. An additional module for cases only and adapted from the Living Conditions Studies recorded perceived cause and history of disability and access to and awareness of rehabilitation services, assistive devices and rights[158]. Figure 3 (overleaf) provides a flow-chart overview of the study protocol.

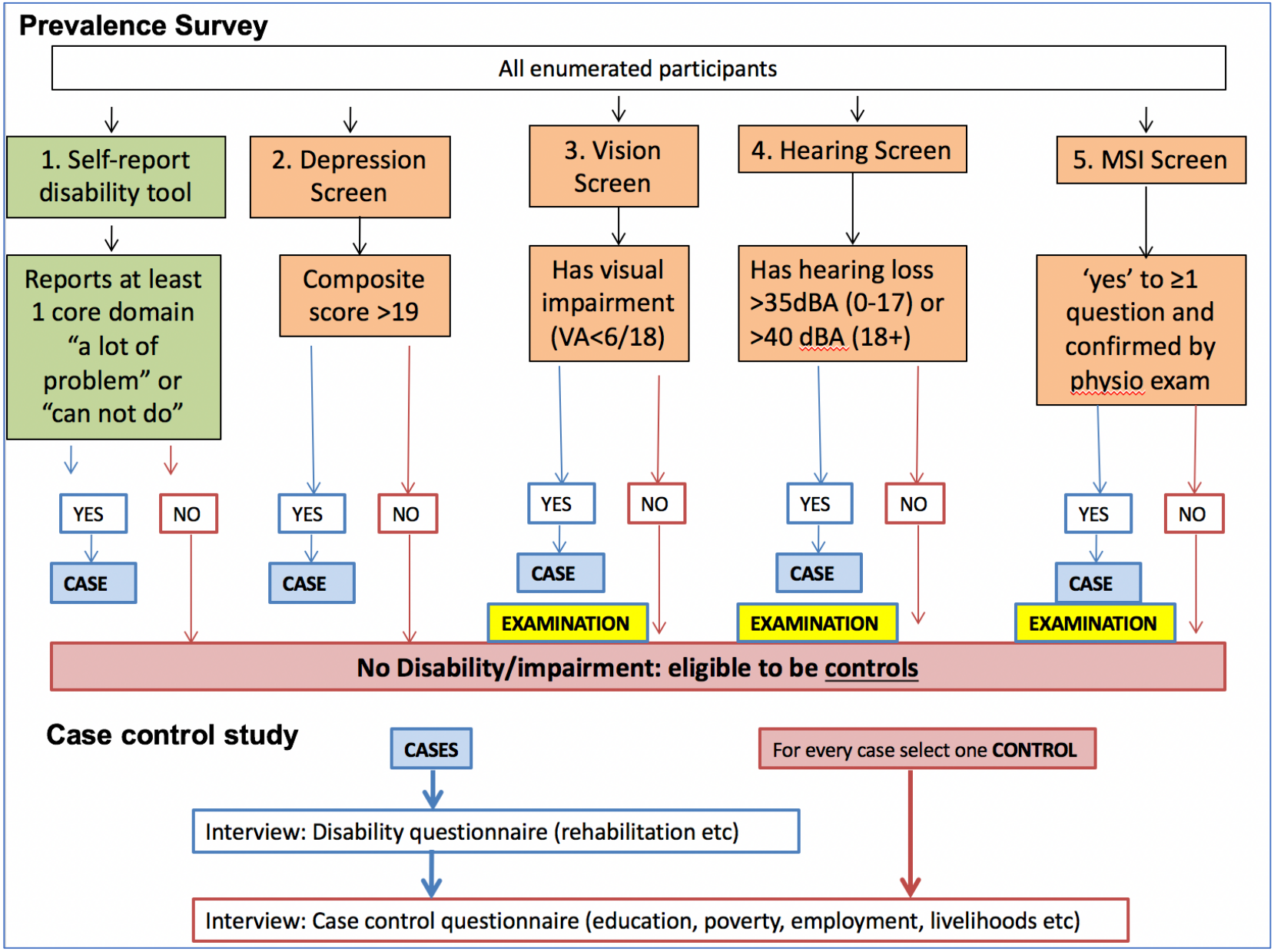


Figure 3: Protocol Overview

4.3 Study Settings

4.3.1 Selection of study settings

In the absence of any prior surveys of this kind, one district-level study site in an African setting, and a second in an Asian setting, were saught. Given the inovative study design, a strong local research partner was necessary in each setting to support the project planning and implementation. Therefore, at the country level, Cameroon and India were selected in accordance with prevailing local research partnerships (namely Sightsavers Cameroon and the Indian Institute for Public Health Hyderabad [IIPHH]) in each.

Sightsavers International is an international organisation combatting avoidable blindness and supporting equality for persons with disabilities, with a large portfolio of programmes across 30 countries[162]. Sightsavers' country office in Cameroon supports a number of river blindness prevention programmes, and the country director has a strong research track record including conducting a number of RAABs.

IIPHH is one of four Institutes of Public Health established by the Public Health Foundation of India (PHFI), to lead Indian public health research, education and training. IIPHH hosts the South Asian Centre for Disability Inclusive Research (SACDIR), and has conducted multiple surveys of disability-related conditions and outcomes[163].

Both Cameroon and India are classified by the World Bank as lower middle income on account of the gross national income per capita [164]. The United Nations Human Development Index - which generates country-level composite scores using indicators of health, life expectancy, education, and standard of living - ranked India 131st and Cameroon 153rd in 2016[164].

The UNCRPD was signed by Cameroon in 2008, but is yet to be ratified[165]. Limited data on disability in Cameroon are available. However a recent study of perceptions of disability amongst University Students in the capital (Yaoundé) identified enduring negative connotations of disability, including one in six students being unwilling to work with a person with a disability in the future[166]. The constrained political environment in Cameroon is stated as a barrier to improved human rights and inclusion in society for people with disabilities in the country[167].

The Persons with Disabilities Act, which legislates the right to equal opportunities and full participation amongst persons with disabilities, was enforced by the National Government of India in 1995[168]. This was followed by a National Policy for Persons with Disabilities in 2006 and ratification of the UNCRPD in 2007[168]

[165]. However, ineffective programmes, insufficient funding and complexities in resource mobilisation are all stated barriers to the realisation of rights as set out in Indian inclusive legislature[169, 170].

The rationale for selecting Fundong Health District, in North West Region, Cameroon and Mahabubnagar District, in Telangana State, India for data collection are provided below.

4.3.2 Fundong Health District, North West Region, Cameroon

Data collection in Cameroon was undertaken in Fundong Health District of North-West Region, Cameroon (estimated population size: 125,604)[171]. North-West Region is 63% rural, whilst data on literacy are not available [172].

Fundong Health District was selected due to its proximity to several health and rehabilitative service providers, and due to English being the primary language in the region. Given the survey methodology, it was determined to be ethically imperative to situate the survey near available services.

Figure 3: Cameroon Study Location

The survey was undertaken in partnership with service providers, policy makers and research institutes including the Cameroon Baptist Church, the NGO-supported Mbingo Baptist Hospital and the Socio-Economic Empowerment of Persons with disabilities (SEEPD) Programme.

4.3.3 Mahabubnagar District, Telangana State, India

The study was conducted in the Northern half of Mahabubnagar District (estimated district population size: 4,053,028) in Telangana State, India[173]. Telangana State

comprises 31 districts and was bifurcated from the State of Andhra Pradesh in 2014, becoming the 29th State of India[174].

According to India's 2011 Census, the population density in Mahabubnagar District is reported to be 220 people/km^2 and the official languages are Telegu and Urdu. 85% of the population live in rural areas, and 48% are literate[173].

Figure 4: India Study Location

Mahabubnagar was selected due to the proximity to available health and rehabilitative services both in Mahabubnagar Town and in the State capital of Hyderabad.

Through IIPHH, we also worked with the Andhra Pradesh Society for Elimination of Rural Poverty (SERP) and the Mahabubnagar District Collector's Office Aarogyshri Scheme.

4.3.4 Inclusion of persons with disabilities

Persons with disabilities were included and consulted at multiple stages of the research study. Persons with disabilities were represented on the study steering group, and were actively recruited to participate in the data collection teams in both study settings. Disabled Persons' Organisations were involved in dissemination in both sites at both the national and local levels.

4.3.5 Community sensitisation and data collection site selection

Relevant government representatives were approached for their written approval of the study and their willingness to assist with relevant information dissemination prior to data collection beginning. Stakeholder mapping was undertaken to

determine appropriate communication flow and protocols to engage stakeholders from State to community level. Village leaders (Village Fons in Cameroon and Sarpanches in India) were approached for permission prior to undertaking any data collection in each cluster. Appendix 4 provides an example of Stakeholder Mapping in India.

4.4 Survey Design

4.4.1 Study Teams

Three study teams in each location, recruited in collaboration with local partners, comprised of the roles depicted in Table 9. In India, one audiologist rotated between the three teams due to constraints in the availability of ear, nose and throat (ENT) personnel. In both settings, local partners were encouraged to identify persons with disabilities for recruitment on the study teams, and to ensure a gender balance across all teams.

Table 9: Study Team Composition in Cameroon and India

Cameroon	India
2 Enumerators/Fieldworkers	2 Enumerators/Fieldworkers
3 Field Workers	3 Field Workers
2 Interviewers	2 interviewers
1 Ophthalmic Nurse	1 Ophthalmic Nurse
1 Orthopaedic Clinical Officer	1 Physiotherapist
1 ENT Nurse	1 Driver + Car
1 Driver + Car	

4.4.2 Sampling

Sample size

Based on previous surveys, we conservatively estimated the prevalence of disability (self-reported functional limitations and/or moderate/severe clinical impairments) to be 4% in India and Cameroon [2, 41]. Assuming precision of 20%, 95% confidence, a design effect of 1.5 and 20% non-response, this required a sample of 4,056 per country, sampled in 51 clusters of eighty. This cluster size was selected

based on prior experience, as the maximum number of participants a team could comfortably collect all necessary data from over two days.

Selection of clusters

Clusters were selected using probability-proportionate-to-size sampling: The most recent census was used as the sampling frame and lowest level census enumeration areas were selected at cumulative population intervals.

The sampling interval was calculated as the total all-age population of the study setting (Funding Health District in Cameroon, and Northern Mahabubnagar District, India) divided by the number of required clusters (fifty-one per site). The first cluster was selected by multiplying the sampling interval by a random number between one and the sampling interval. Subsequent clusters were selected by adding the sampling interval to the previous number, resulting in a list of clusters selected with probability proportionate to size.

Selection of participants within clusters

Within clusters, participants were selected using compact segment sampling conducted by enumerators 1-2 days before the survey. Using existing maps, or sketch maps drawn by community members, clusters were divided into segments of approximately 80 people. One segment was randomly selected for inclusion in the survey.

Photo 2: Community Leaders Sketching a Map, Cameroon

Community leaders of selected clusters were informed in writing in advance about the survey and were visited by enumerators to attain verbal permission to conduct the study in their locality before enumeration was undertaken in each cluster.

Enumerators then worked with community leaders to segment sketched or existing maps and, once a segment had been selected at random, determine a central non-religious, non-political community location to undertake the data collection.
A village guide (often selected by the community leader) known to the community was selected in each cluster to assist and accompany enumerators, mobilise participants and minimise non-response. In Cameroon this tended to be Community Health Workers whilst in India these were predominantly Accredited Social Health Activists (ASHA).

Enumeration and participant eligibility

On arriving at each household in the segment, enumerators explained the study purpose and protocol to the household head or an eligible, adult key informant. Verbal consent on behalf of all household members was sought and if s/he agreed to participate, the enumerator recorded the name, age, gender and relationship to household head of all eligible household members. A GPS point-reading and basic observed socio-economic indicators (building materials for household roof, walls and floor) were also recorded.

Photo 3: Participant arriving for enumeration at central location, India

Eligible household members were defined as any person, any age, who 1) had stayed in the house at least six months of the last year, 2) ate shared meals and 3) did not pay rent to other household members.

Enumerators visited each house within the segment door-to-door until 80 eligible participants had been recorded. All eligible household members were invited to attend the survey screening at a central village location the following day.

If the total number of 80 eligible participants was completed within a household, the required number of participants needed to complete the cluster were selected at random from eligible household members within that house. Non-selected household members were welcome to attend the survey screening and referred to the relevant service if unmet needs were identified, but their data was not collected. If fewer than 80 eligible participants were identified within the segment, a second segment was selected at random from within the same cluster to complete the enumeration.

4.4.3 Screening Protocols and disability prevalence case definitions

All participants who attended the screening were read an information sheet about the study (Appendix 2) and given the opportunity to ask questions. If they agreed to participate, they were asked to provide witnessed written or (if illiterate) finger print consent. For children <18 years in India and <21 years in Cameroon a caregiver was required to provide witnessed written/finger print consent and to remain present throughout the data collection process.

All participants (≥2 years) underwent screening for self-reported functional limitations, as well as impairment screening (all ages) for vision, hearing, epilepsy and MSI. Participants aged 18+ were also screened for depression.

Protocols for each screen are described below, including examination and referral protocols.

Disability Prevalence Estimate Criteria

Participants were included in the disability prevalence estimate if they reported significant functional limitations or were identified to have a moderate or worse impairment, epilepsy or severe depression. Despite the recognised limitations of considering impairment as a proxy for disability (see section 1.1), these were included in the prevalence estimate so as to assess the inter-relationship and relative merit of these different approaches within population-based disability measurement compatible with the ICF. Responses to the single question in India

(not collected in Cameroon) were not taken into account in estimating the prevalence of disability in the survey. Eligibility criteria for inclusion in the nested Case-Control study are described in Section 4.5. The full screening questionnaire is available in Appendix 3.

Self-Reported Functional Limitations

Self-reported functional limitations were assessed using the UNICEF/Washington Group Draft Module on Child Functioning (ES-F) for children 2 to 17 and the Washington Group Extended Set on Functioning (ES-F) for adults aged 18 and above. No validated tool was available for reported functional limitations amongst infants less than 2 years.

Ages 2- 17: UNICEF/ Washington Group Draft Module on Child Functioning

Table 10 below provides the domains included in the UNICEF/Washington Group Draft Module on Child Functioning, including domains with age-group appropriate variations, and response options. Domains on seeing and hearing include supplementary information on assistive device use.

To standardize proxy-respondent responses to generally accepted stages of child development, where appropriate, questions were prefaced with the clause "*compared with children of the same age*. . ." .

Parents or adult primary caregivers reported for children under the age of 9 or for older children who were unable to communicate independently. Children aged 9 and above were interviewed directly where feasible and appropriate.

Table 10: UNICEF/ Washington Group Draft Module on Child Functioning Domains		
Age Group	**Domain**	**Response Categories**
2 – 17 years	Seeing[1]	No difficulty, some difficulty, a lot of difficulty, cannot do
	Hearing[1]	
	Walking	
	Communicating (understanding or being understood)[2]	
	Learning[2]	
	Behaviour[2]	2 – 4 years The same or less, more, or a lot more 5 – 17 years No difficulty, some difficulty, a lot of difficulty, cannot do
	Playing[2]	No difficulty, some difficulty, a lot of difficulty, cannot do
5 – 17 years only	Self-care	
	Remembering	
	Completing a task	
	Accepting Change	
	Getting along with others	
	Worry/Sadness	The same or less, more, a lot more
[1]Includes separate question on access to assistive devices [2]Age appropriate variation for ages 2-4 and 5-17		

At the time of data collection, the Child Functioning Module was under development. Through consultation with the tool's developers and in synergy with the Washington Group ES-F for adults, the following disability case definition was used to allow estimation of prevalence:

Self-Reported Significant Functional Limitation Case Definition: Reporting "*a lot of difficulty*" or "*cannot do*" to any one of the following domains: seeing, hearing, walking, self-care, communicating, learning, remembering

Age ≥ 18: Washington Group Extended Set on Functioning (ES-F) for Adults

Table 11 below outlines the domains included in the ES-F for adults aged 18 and above, including response options. Domains on seeing, hearing, walking and communicating include supplementary information on assistive device use, whilst domains related to affect (anxiety or depression) include information on whether

medication is taken to control feelings. In addition, domains related to affect, pain and fatigue include supplementary information on intensity of feelings.

All adults age ≥18 self-reported unless available to communicate independently, in which a proxy provided responses.

Table 11: Washington Group Extended Set on Functioning (ES-F) for Adult Domains

Domain	Response Categories
Seeing[1]	No difficulty, some difficulty, a lot of difficulty, cannot do
Hearing[1]	
Mobility (walking or climbing steps)[1]	
Communicating[1]	
Remembering or concentrating	
Self-care	
Upper body strength	
Fine motor dexterity	
Feeling worried, nervous or anxious[2,3]	Daily, weekly, monthly, a few times a year, never
Feeling depressed[2,3]	
Pain[3]	Never, Some Days, Most Days, Every Day
Fatigue[3]	
[1]Includes separate question on access to assistive devices [2] Includes supplementary information on whether or not medication taken [3]Includes supplementary information on intensity of feeling (a little, a lot, in between a little and a lot)	

At the time of data collection, agreed cut-offs for population disability prevalence estimates using the ES-F had not been determined. Domains related to affect (i.e. feeling worried, nervous or anxious, or feeling depressed) were still in early stages of development. Therefore, through consultation with the tool's developers, the following disability prevalence case definition was used:

Self-Reported Significant Functional Limitation Case Definition: Reporting "*a lot of difficulty*" or "*cannot do*" to any one of the following domains: seeing, hearing, mobility, communicating, remembering or concentrating, self-care, upper body strength, fine motor dexterity

Self-reported disability

In India, a single question "*do you consider yourself to have a disability*?" was included for adults and the single question "*do you consider yourself [age 9–17]/your child [age 2–8] to have a disability*?" was included for children. The single question was included for comparison purposes, given its prior use in numerous population-based census and other large data sets. Responses to this question were not taken into account in the overall disability prevalence estimate.

Visual Impairment

An adapted version of the Rapid Assessment of Avoidable Blindness was used to measure visual impairment[77]. Methods for assessment of young children were adopted from the WHO Prevention of Blindness and Deafness Programme (WHO/PBD) standardised form for the assessment of visual loss in children [106]. Age-disaggregated protocols for all age groups are described below.

Ages 0 – 2: Fix and Follow: Ophthalmic nurses/assistants used a red pen (with lid) to determine whether the infant was able to fix and follow the pen as it moved.

Moderate or worse Impairment Case Definition: Cannot fix and follow

Age 3 – 4: Counting Fingers: Presenting vision was tested i.e. with the child wearing glasses if they normally use them. Data collectors stood near to the child and showed them a number of fingers, asking the child to copy them. This process was repeated up to four times to ensure that the child understood the task. The data collector then moved six metres from the child, using a pre-measured piece of string. The data collector asked the child to copy the number of fingers shown on five consecutive attempts.

Moderate or worse Impairment Case Definition: Cannot count fingers

Age 5+: Visual Acuity Testing using Tumbling 'E' Chart: Presenting vision was tested. Visual acuity was measured using a vision chart with an 'E' optotype of size 18 on

one side and size 60 on the other side. In India, a third 'E' optotype with size 12 on both sides was used in addition.

Participants were tested in full daylight, with the participant standing or sitting in the shade with his or her back to the sun. The right eye was tested first, whilst the left eye was completely covered using the palm of a hand or an occluder, either by the participant or by a data collector.

First, the size 60 optotype ('big E') was shown at close proximity, to check understanding. The procedure was explained by asking the participant to point in the direction of the open ends of the 'E' a number of times. For each test, the 'E' was rotated to change the direction of the open ends. Rotation was varied in pattern to avoid memorising.

Photo 4: Visual Acuity Testing, Cameroon

Once the participant understood the procedure, the data collector moved to 6 metres distance using a pre-measured piece of string. The data collector began by asking the participant to point in the direction of the prongs of the big E. If the participant was able to correctly identify the direction at 6 metres (6/60), they repeated the screen with the size 18 E to ascertain if the participant was able to see 6/18. In India, if the participant was correctly able to see at 6/18, the test was repeated with a size 12 to ascertain whether the participant was able to see 6/12.

If the participant was unable to see the big E at 6 metres, the data collector moved to three metres, and repeated the test using the same size E (3/60). If the participant could not see the big E at three metres, the data collector moved to one metre and repeated the test using the same size E (1/60). If the 'big E' could not be seen at one

metre, the ophthalmologist used a torch in a semi-dark condition (e.g. inside the participant's house) to determine whether the participant had perception of light (PL+) or not (PL-).

Vision was also tested using a pinhole occluder for all eyes with VA less than 6/18 in Cameroon and less than 6/12 in India. Pinhole testing was performed to determine the presence of uncorrected refractive error.

Severity of visual impairment was classified according to the WHO classification of visual impairment and blindness as shown in Table 12. All classifications are based on presenting vision in the better eye.

Table 12: WHO classifications of visual impairment and blindness	
Visual Acuity	**Classification**
≤6/12	Normal Vision
>6/12 and ≤6/18	Early Vision Impairment
>6/18 and ≤6/60	Moderate Vision Impairment
>6/60 and ≤3/60	Severe Vision Impairment
>3/60	Blind

Moderate or Worse Impairment Case Definition: VA<6/18 in the better eye

Table 13 below summarises the case definitions for moderate or worse vision impairment across the different age groups.

Table 13: Summary of cut offs for Moderate or worse Visual Impairment		
Age Group	**Screening Method**	**Definition of a case**
0-2 years	Fix and follow	Cannot fix or follow
3-4 years	Counting fingers	Cannot count fingers
≥5 years	Visual Acuity using -E chart	VA <6/18 in better eye (presenting)

Hearing Impairment

A modified version of the WHO/PBD Ear and Hearing Disorders Examination protocol was used for all age groups [78].

All participants of all ages underwent initial screening using an otoacoustic emissions (OAE) test administered via an OAE machine to assess middle ear function in both ears. Cavity tests were performed daily to confirm functionality of the machines, and disposable probe tips were used for each participant.

Participants aged four and above who failed the OAE test in both ears, or for whom OAE readings could not be taken, underwent Pure Tone Audiometry Screening to assess the level of hearing impairment. Pure Tone Audiometry was not administered to those under 4 years old due to the requirement of participant response. Audiometry self-calibration was performed by the ENT nurse or fieldworker daily to confirm functionality. Hearing in each ear was measured in weighted decibels (dBa) at frequencies of 1Kilo-hertz (KHz), 2 KHz, 4 KHz, 0.5KHz and again at 1KHz to ensure consistency of response. If the first and second 1KHz readings did not match (+/- 5 dBHa), the test was repeated. The average reading for each ear across the 4 frequencies was recorded as the Pure Tone Average (PTA).

Photo 5: Pure Tone Audiometry Testing,

Notably, recommended threshold cut-offs for hearing impairment classification vary between WHO and GBD recommendations. Whilst the former recommend separate minimum thresholds for moderate or worse hearing impairments (also termed "*disabling hearing impairment*") in adults and children of PTA in the better ear of ≥41dba and ≥31dba respectively, the GDB recommends a threshold of ≥35dBa irrespective of age [48, 108].

For the purposes of the study, classifications of hearing impairment and deafness based on PTA are defined per age-group as in Table 14 below. All classifications are based on presenting hearing in the better ear.

Table 14: Study Classifications of hearing impairment and deafness		
Age Group	**Pure Tone Average**	**Classification**
5 – 17	<25 dBHa	Normal Hearing
	≥25 and <35 dBHa	Mild Hearing Impairment
	≥35 and <61 dbHa	Moderate Hearing Impairment
	≥61 and <81 dbHa	Severe Hearing Impairment
	≥81 dbHa	Profound Hearing Impairment (deaf)
18+	<25 dBHa	Normal Hearing
	≥25 and <41 dBHa	Mild Hearing Impairment
	≥41 and <61 dbHa	Moderate Hearing Impairment
	≥61 and <81 dbHa	Severe Hearing Impairment
	≥81 dbHa	Profound Hearing Impairment (deaf)

Moderate or worse impairment Case Definition: 5-17 PTA ≥ 35dBA in better ear, 18+ PTA ≥41dBA in better ear

Table 15: Summary of Disability Prevalence Cases Definitions for Hearing Impairment		
Age Group	**Screening Method**	**Definition of a case**
0-4	OAE	Failure of OAE in both ears
5 – 17	OAE + PTA	Failure of OAE in both ears and average PTA ≥35 dBa in better ear
18+	OAE + PTA	Failure of OAE in both ears and average PTA ≥41 dBa in better ear

Musculoskeletal Impairment (MSI)

The Rapid Assessment of Musculoskeletal Impairment (RAM) was developed by members of the International Centre for Evidence in Disability (ICED) at the London School of Hygiene & Tropical Medicine (LSHTM) in the absence of pre-existing MSI assessment tools[96]. This tool was previously used to conduct a large scale population-based survey on MSI in Rwanda.

Six initial screening questions were administered by a field assistant. These were reported on a binary yes/no format and determined:

- Whether the participant considered any body part to be missing or misshapen
- Whether they had difficulty using their arms
- Whether they had difficulty using their legs
- Whether they had difficulty using another part of their body
- Whether they felt they had need for a mobility aid or prosthesis
- Whether they experienced convulsions, involuntary movements, rigidity or loss of consciousness
- In India, an additional question on difficulty with back pain was added based on pilot test feedback

Any participant responding affirmatively to any of the screening questions was asked the duration of their limitation (has it lasted more than one month, and is it permanent). If the participant responded that the limitation was permanent, or had lasted more than one month, they underwent an observation of activity assessment, questioning and examination by the team Orthopaedic Clinical Officer or Physiotherapist, to determine the presence and level of musculoskeletal impairment.

Examination included standardised observation of activities (e.g. walking and picking up small items) to assess functioning. Based on these examinations, the participant was categorised as having either mild, moderate or severe musculoskeletal impairment as shown in Table 16.

Photo 6: MSI Examination, India

Table 16: Study Classifications of Musculoskeletal Impairment	
Clinician Observation	**Classification**
Despite having screened positive for MSI, on further examination it is determined that the participant does not have MSI	Non-case
Determine from assessment that the persons impairment has a mild effect on the ability of their musculoskeletal system to function as a whole (5-24%) e.g. polydactyly	Mild Impairment
Determine from assessment that the persons impairment has a moderate effect on the ability of their musculoskeletal system to function as a whole (25-49%) e.g. club foot	Moderate Impairment
Determine from assessment that the persons impairment has a severe effect on the ability of their musculoskeletal system to function as a whole (50-100%) e.g. quadriplegia	Severe Impairment

Moderate or worse Impairment Case Definition: Moderate or Severe MSI, or presence of epilepsy determined by three or more tonic-clonic seizures in previous twelve months.

Clinical Depression

Participants aged 18+ were screened for depression using The Patient Health Questionnaire (PHQ-9). The PHQ-9 was developed as a simple self- or interviewer-administered diagnostic and severity measurement tool to diagnose specific disorders within the framework of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSIM-IV)[175].

The lack of validated tools for other Common Mental Disorders (CMDs) limited the study's ability to assess CMDs beyond Clinical Depression. Moreover, psychosocial and intellectual impairment were also excluded based on the lack of available tools. Given that perceptions related to depression are culturally dependent, the PHQ-9 – which has previously been validated in both Cameroon and India – was selected for use in the study[121, 122, 176].

The PHQ-9 uses the preamble "*over the last two weeks, how often have you been bothered by any of the following problems*" and consists of three screening questions

and six additional questions related to symptoms of depression. Response categories for each question are "*not at all*", "*several days*", "*more than half the days*" and "*nearly every day*".

Participants responding "*more than half the days*" or "*nearly every day*" to any of three initial screening questions are asked a further six questions. Based on a composite score across the nine questions, a diagnosis and severity threshold for mental disorders is established (Table 17).

Table 17: Study Classifications of Clinical Depression

PHQ-9 Score	Classification
0 – 4	None
5 – 9	Mild
10 – 14	Moderate
15 – 19	Moderately Severe
20 – 27	Severe

Moderate or worse Case Definition: Composite score 10 or more.

Aetiology of Impairment

All participants identified to have impairments in vision, hearing or MSI were examined by the relevant clinical team member. Participants with any level of vision impairment underwent a lens examination by the ophthalmologist to determine cause of visual impairment. Participants with average PTA ≥35dBa (0-17years) or ≥41dBa (18+years) in both ears were examined by the ENT nurse/audiologist using an otoscope to determine cause of hearing loss and actions needed. Simple interventions (such as impacted wax removal) were performed by the ENT nurse/audiologist, and participants were referred for more complex interventions. The physiotherapist examined all participants who reported difficulties in the RAM tool. Up to two diagnoses were permissible per identified case of MSI, and aetiology was recorded where it was known by asking the participants about when and how the impairment developed.

Analysis of cause data is beyond the scope of this thesis. However, refer to Appendix 1 for selected manuscripts related to prevalence and aetiology of impairment data.

4.5 Nested Case-Control study methodology

The objectives of the nested Case-Control study were:

1. To determine the lived experience of disability and whether persons with disabilities experience equal opportunities in their societies.
2. To identify contextual predictors of access to health, education and employment among persons with disabilities

4.5.1 Selection of Cases

Cases for the case-control study were restricted to participants aged ≥5years with significant self-reported functional limitations or moderate or worse clinical impairments, epilepsy or moderately depression as pre-defined by authors of each tool/ standard classifications.

Children <5 years were excluded from the Case-Control study based on the limited exposure that children of this age group have to external activities and services beyond the household [177].

Table 18 summarises case definitions for eligibility into the Case-Control study across all screening tools used.

Table 18: Eligibility for Case-Control Study (all age 5+)

Component of Disability	Tool Name	Age Group	Eligibility for Case-Control Study (significant reported functional limitation or moderate/worse clinical impairment)
Self-reported functional limitations	UNICEF/ WG ES-F	5-17	Response of 'a lot of difficulty' or 'cannot do at all' in one of the following domains: seeing, hearing, walking, self-care, understanding, being understood, learning, remembering

	WG ES-F	18+	Response of 'a lot of difficulty' or 'cannot do at all' in one of the following domains: seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care, upper body strength, fine motor dexterity
Visual Impairment	RAAB	5+	Presenting visual Acuity <6/18 in better eye (moderate visual impairment)
Hearing Impairment	WHO/PBD Ear & Hearing Form	5-17	OAE failure in both ears and PTA reading >35dBa in both ears (moderate hearing impairment)
		18+	OAE failure in both ears and PTA reading >40dBa in both ears (moderate hearing impairment)
Musculoskeletal impairment	RAM	5+	Moderate MSI as determined by physiotherapist
Clinical Depression	PHQ-9	18+	Composite score of 19 or above (severe clinical depression)

Photo 7: Case-Control interview participant

Additional case finding

We estimated that the sample size for the population based survey would identify approximately 160 eligible participants with disabilities age 5 and above. Of these

we expected 50 to be children 5 – 17 and 110 to be adults 18 and above. The sample size was sufficient to measure prevalence, but in order to identify enough subjects for the case control study, we sought to identify a further 50 adults and 110 children with disabilities through case finding in each cluster using local key informants.

Enumerators asked key informants to identify one adult and two children per cluster with a disability, from within the cluster but outside the selected segment. The survey team then visited their households and undertook the impairment and disability screening as described above. This process was estimated to provide sufficient sample size to assess the impact of disability on our key variables: poverty, quality of life and access to health care, livelihood and education.

This approach was necessitated by logistical and budget constraints that prevented further expansion of the survey sample size. However, it is acknowledged that this method is likely to have identified individuals with more 'obvious' and severe disabilities, and potentially missed those with more hidden impairments such as mild/moderate cognitive or hearing limitations.

4.5.2 Selection of controls

For every case identified we selected one age, sex and cluster matched control without a disability (according to the study criteria). Controls and cases were matched by age (±3 year for children 5-17 years; ±10 years for adults≥18 years). Controls were identified at random from amongst those in the cluster not meeting the criteria in Table 18. Furthermore, eligible controls were drawn from households in which no member or the household met the case criteria.

4.5.3 Questionnaire design and development

The Case-Control Questionnaire contains the components outlined in Table 18 below. The table also notes the source of these questions. The full questionnaire is shown in Appendix 3.

Table 18: Case-Control Questionnaire		
Component	**Source**	**Details**
Cover Sheet	Developed internally	Participant identifiers and personal demographics
Socio-economic indicators	World Bank Living Standards Measures Survey [161]	Household ownership of country-relevant assets (e.g. radio, TV, Table), main source of household lighting and number of rooms.
Water and Sanitation	WHO Joint Monitoring Programme for Water Supply and Sanitation [178]	Toilet type and use, water source and use
Marital Status, Literacy and Education (aged ≥18)	World Bank Living Standards Measures Survey and Demographic Health Surveys [160, 161]	Marital Status, literacy, past education enrolment and attainment, household head education
Education (aged <18)	The African Child Policy Forum (ACPF) Survey on children with disabilities (2009) in collaboration with the Ethiopian Centre for Disability and Development (ECDD)[179]	Participant enrolment, grade, repetition, school experience and reasons not in school
Livelihood (aged ≥18)	World Bank Living Standards Measures Survey [161]	Type and duration of work, payment, reasons not working, benefits received
Health and Antenatal Care	World Bank Living Standards Measures Survey and Demographic Health Surveys [160, 161]	Recent health problems and health seeking behaviour, reproductive health (women aged 15-49), pregnancy care (women with children <5)
Activity Limitations and Participation Restrictions	SINTEF Living Conditions Study [83]	Domains of activity limitation (sensory experiences, basic learning and applying knowledge, communication) and participation (mobility, self-care, domestic life, interpersonal behaviours, major life areas and community; and social and civil life)
Environment	SINTEF Living Conditions Study [83]	Reported environmental barriers to participation (including frequency and strength of barrier)

Disability-specific module (Cases only)	SINTEF Living Conditions Study, WHO Joint Monitoring Programme for Water Supply and Sanitation [83, 178]	Perceived causality of disability; Knowledge of, perceived need of and access to assistive devices and rehabilitative services; access to inclusive education (Cases ≥17); access to inclusive Water and Sanitation; access to disability benefits

Participants were interviewed by trained interviewers in a private space at the screening location. The primary caregiver remained present throughout interviews for children <21 years in Cameroon and <18 years in India.

4.6 Other Methodological Considerations

4.6.1 Translation

Cameroon

The primary language in the Cameroon study site was English, whilst the population also spoke two non-written languages – Pidgin English and Nkom. The full questionnaires were therefore not translated from English, but interviewers fluent in the non-written languages were included on each team. In situations where participants were fluent in Pidgin English or Nkom only, the interviewers verbally translated the questionnaires. During training, the quality of the verbal translation into these languages was assessed for each interviewer: the interviewer asked the question in the local language and an independent person translated this back into English. Differences were noted and discussed. In addition, through group discussion with team members, a phrase-sheet of phonetic standard translations of key terms (e.g. depression, anxiety, assets) was developed to ensure consistency.

India

In India, all questionnaires were translated into Urdu and Telegu, the two official languages of Telangana State. Questionnaires were forward translated by a member of the study team before being back translated into English by a professional translator. Based on the back-translation, minor modifications were made as necessary.

4.6.2 Pilot testing

Manson (1997) states that satisfactory translation of reported screening tools must be comprehensible (item meaning understood), acceptable (inoffensive), relevant (item effectively measures construct of interest) and complete (equally understood across contexts and participant groups)[180].

In both settings, the questionnaires were cognitively tested and checked for context relevance. Cognitive testing of the questionnaires was carried out in Cameroon in July 2013 and in India in February 2014 to assess feasibility and understanding. This involved completing interviews with local volunteers (both adults and children, and with and without disabilities) and probing their reasons for responses given. For the case-control questionnaire, this also involved testing whether pre-coded response options were appropriate. The cognitive testing resulted in a small number of changes to improve clarity of wording in both settings, and several questions (n=~4) deemed context-irrelevant were removed.

Post training, the full survey protocol was pilot tested in one local community near the training site, but not included in enumerated clusters. In each setting, this involved each team completing the full survey protocol with 30 volunteers.

Several changes were made to the protocol following the pilot in Cameroon. Using the adult WG ES-F questions, a large proportion of the adult population reported "*a lot*" or greater difficulty in response to the tiredness/pain questions. Case definitions for self-reported disability were therefore restricted to core domains

(see Section 4.4.3), after discussion with the tool's developers. No changes to the protocol were made following pilot testing in India.

4.6.3 Training

Training in each site lasted for 9 days and included tool-specific training and practice, alongside overviews of disability concepts, ethics and survey protocol.

Interobserver-reliability was tested for all impairment tools to ensure consistency across the teams in each setting. For inter-observer variation testing, each of the three teams examined the same 20-30 patients attending vision, hearing or physiotherapy clinics as appropriate. In the absence of reference-standard diagnostic tests, the most experienced clinician in each setting was defined as the gold standard (i.e. the best available test) [181]. In line with similar field methodologies (e.g. the RAAB), a kappa coefficient of inter-observer variation was calculated to measure the agreement between the screening diagnoses maintained by the gold standard and each other clinician independently, to assess the quality and consistency of diagnoses across the team. Based on the prevailing literature, a kappa score of >0.6 (where 1.0 equals perfect agreement and 0.0 equals agreement equivalent to chance) was considered acceptable[182].

Photo 8: Training, Cameroon

4.6.4 Ethical considerations

Ethical Approval for the study was granted by:

- The London School of Hygiene and Tropical Medicine (London, UK)
- The National Ethics Committee for Research in Human Health (CNERSH, Cameroon)
- The Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon)
- The Public Health Foundation of India Institutional Ethics Committee (India)
- The Government of India Health Ministry Screening Committee (India)

Referral services available in the region were mapped pre-emptively to ensure appropriate onward referral for any individuals identified with unmet healthcare needs.

In Cameroon, clinical team members provided referrals to partner organisations as appropriate. All identified cases in the study, regardless of health or other need, were given information about the local Community-Based Rehabilitation program (SEEPD, the Socio Economic Empowerment for Persons with Disabilities Programme) for additional support in education, livelihoods, benefits etc. Follow up support was provided at the end of the study, with field teams re-contacting all participants who had been offered medical and rehabilitative referrals to provide additional information and logistical support.

In India, all identified cases in the study were given information for the local Andhra Pradesh Society for Elimination of Rural Poverty (SERP) coordinator and the Aarorgya Mitra Scheme Registry program for additional support in education, health, livelihoods, benefits etc. Follow up support was provided at the end of the study, with field teams re-contacting all 681 participants who had been offered medical and rehabilitative referrals to provide additional information and offer logistical support. Amongst these, 231 participants were directly assisted in attending follow-up referrals.

Basic medicines (vitamins, anti-inflammatories, ear and eye drops) were distributed by clinical team members, where appropriate.

4.6.5 Data entry

Screening Questionnaire

The Screening Questionnaire results were recorded using paper questionnaires and 1) checked by the team leader for completion in each cluster 2) checked by the project coordinator (IM) prior to data entry. Data were then double entered into a purpose-built Microsoft Access Database by two trained Data Entry Clerks in each setting. Data were corrected for inconsistencies between entries using the EpiInfo Data Compare utility and merged in STATA 12.0 for analysis. Due to the need for multiple team members to complete separate sections of the Screening Questionnaire, this approach was determined to be preferable to mobile data entry (see below).

Case-Control Questionnaire

The Case-Control Questionnaire was created on Microsoft Excel, transformed into a .xml file using the XLSForm software, and uploaded to a secure cloud based server using the Open Data Kit software (see Figure 4). The questionnaire was then administered using ASUS Google Nexus 7 tablets. Data collected on each tablet was transferred daily via Wi-Fi connection, with results backed up weekly onto a secured portable hard drive. The use of mobile data entry minimises data entry errors by providing inbuilt logical skip-patterns and preventing the finalisation of forms with missing data.

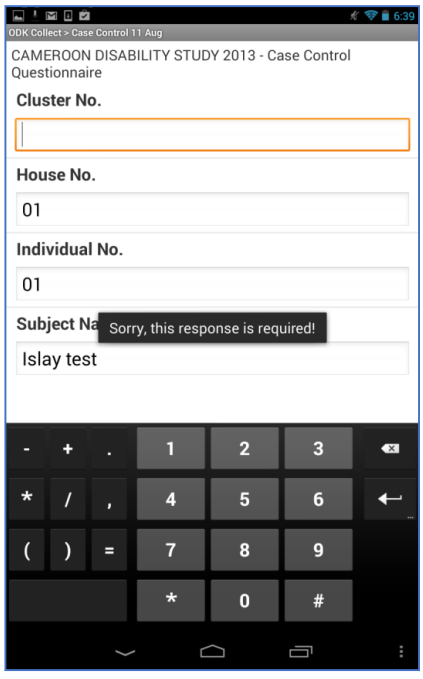


Figure 4: Case Control Questionnaire

Data from both the Screening Questionnaire and the Case-Control Questionnaire were merged in STATA 12.0 for data cleaning and analysis.

4.6.6 Data analysis

Data analysis across the research objectives are summarised below and specified in detail in the relevant chapters.

Assessing the prevalence of disability

The 'svy' command was used to derive prevalence estimates accounting for cluster sampling in Chapters Five, Six and Seven. Prevalence estimates are presented as percentages with 95% confidence intervals (CI), disaggregated by age group and gender.

Functional domain-specific analyses are reported as 'at least some difficulty' and 'at least a lot of difficulty', given small numbers. Associations between reported limitations in Chapter Five (both aggregate domains and for each specific domain), age group and gender were assessed using a Chi-squared test of association. Pearson's correlation coefficient analysis (r) was computed to assess pairwise relationships between endorsed domains.

Exploring the relationship between measures of objectively-measured impairment and self-reported functional limitations

Overall agreement between objective impairment and self-reported functional limitation measures was examined using Venn diagram proportions (Chapter Six). Predictors of the agreement between the different disability measures were analysed using logistic regression. Specifically, demographic (age, sex) and impairment-related (severity, type) predictors of people with clinical impairments also reporting functional limitations were assessed. Mean participation scores among participants screening positive for i) impairment and ii) functional limitation were compared using the student t-test.

The agreement between reported difficulties with vision, hearing, mobility and the corresponding clinical impairment were also assessed (Chapter Eight). Analyses were restricted to participants eligible for both clinical screening and self-reported

tools (i.e. age 2+), and to those for whom there was no missing data for either measure.

Cross-tabulations were conducted to describe the relationship between:

i) Any level reported functional limitation in seeing and any level visual impairment
ii) Any level reported limitation in hearing and any level hearing impairment
iii) Any level reported limitation in walking, climbing, upper body strength and fine motor skills and any level musculoskeletal impairment
iv) Any level of reported limitation and any level clinical impairment aggregated across the domains above.

For each pair (e.g. vision impairment and reported difficulty with seeing), crude numbers and row-wise percentages are reported for i) no impairment, ii) each severity level of impairment and iii) any level of impairment; tabulated against i) no reported difficulty, ii) 'some' reported difficulty, iii) 'a lot' of reported difficulty and iv) 'extreme/cannot do' in the relevant self-reported domain.

To assist exploration of the inter-relationship between approaches, Sensitivity, Specificity, Positive Predictive Value (PPV) and Negative Predictive Value (NPV) were calculated with the impairment considered the 'gold standard' and the self-reported domain as the test. This does not imply that the impairment tool was considered superior, but aimed to assess agreement across the two approaches.

Agreement of self-report in comparison to clinical impairment was explored in four ways for each pair:

- Any level impairment versus 'some' or greater reported difficulty
- Any level impairment versus 'a lot' or greater reported difficulty
- Moderate or worse impairment (as used in disability prevalence estimates) versus 'some' or greater reported difficulty

- Moderate or worse impairment (as used in disability prevalence estimates) versus 'a lot' or greater reported difficulty

Assessing the lived experience of disability

Descriptive analyses were undertaken to describe the age range, sex and socio-economic status of the cohort, alongside attributes of disability amongst persons with disabilities (disability type, age of onset and severity).

A socio-economic status score was constructed through principal component analysis (PCA) of household assets. The PCA score distribution amongst controls was used to define the interquartile range, with cases then categorised into quartiles based on control 'cut-points'[183].

Multivariable logistic regression analyses were undertaken to identify differences between cases and controls in terms of health, education, livelihoods and WASH (Chapters Nine to Twelve). Binary variables were created for marital status (married versus never married, widowed or divorced) and education (no education versus at least one year of education). Conditional logistic regression was not attempted since matching was not complete, and so analyses were adjusted by the matching variables of age and gender, in addition to socio-economic status. The 'vce' command was used to calculate robust standard errors accounting for the heteroscedasticity of the sample in relation to clustering.

In the analysis of the livelihoods data (Chapter Ten), the primary outcome variable 'working' for adults aged 18 and above was defined as having undertaken any activities contributing to household consumption (inclusive of subsistence farming and remuneration for any activity in cash or kind). Logistic regression analyses were undertaken, adjusted for age and sex to compare participation in education (age 5-17) and work (18+) between cases and controls stratified by age, sex, socio-economic status (SES), marital status and education.

Logistic regression analyses adjusted for age and sex were also undertaken for children 5-17 in Chapter Eleven to compare a) current enrolment b) current and

repeated grades c) school absences and d) school participation between children with and without disabilities. Descriptive analyses only were undertaken to describe attributes (e.g. previous school attendance and barriers to attendance) of children with disabilities out of school given the low quantity of children without disabilities in this group.

Following Mizunoya et al.(2016)'s methodology, the attendance gap between children with and without disabilities was calculated as the percentage point difference between the percentage of children with disabilities out of school minus the percentage of children without disabilities out of school [52].

The Education Participation Restriction module consisted of 9 items rated using Likert scale response (always, sometimes, never)[179]. A binary variable of 'always' versus 'sometimes' or 'never' was created, and used to calculate an average total summated score and scores for three sub-scales: Inclusive school environment (items on teacher support, inclusion in lessons and school and accessible learning materials); Peer support (support from friends, friends coming to you for support, friends to play with and friends looking to you as leader); and experience of violence (violence inflicted by teachers or peers). 'Don't Know' responses were converted to missing data and excluded from analyses related to the relevant item/sub scale. Cronbach's alpha (α) of internal consistency was calculated for each sub-scale and the total scale to assess internal consistency was of an acceptable level ($\alpha \geq 0.7$) as per guidelines for scale reliability [184].

Identifying predictors of access to health, education and employment among persons with disabilities

Multivariable logistic regression, adjusted for confounders, was undertaken to explore predictors of access to employment, education and WASH amongst adults and children with disabilities respectively, in Chapters Ten, Eleven and Twelve. The composition of predictors related to 'type' of disability, severity of limitation and demographics are summarised below.

Six binary, non-mutually-exclusive, variables for 'type' of disability were constructed based on a combination of the clinical and self-reported results.

These were:

- Vision: VA<6/18, or reported 'a lot of difficulty' or 'cannot do' in the vision domain of the WG questions
- Hearing: Presenting average hearing threshold in better ear of >40dBA, or reported 'a lot of difficulty' or 'cannot do' in the hearing domain of the WG questions
- Physical Function: Structure impairment of 25-49% or greater, screens positive for epilepsy, or reported 'a lot of difficulty' or 'cannot do' in the physical domain of the WG questions
- Intellectual Function: Reported 'a lot of difficulty' or 'cannot do' in the learning and understanding domains of WG questions
- Depression: score of 20 or above on PHQ-9
- Multiple: More than one of the above.

Severity of limitation was calculated amongst cases as 'moderate' or 'severe/profound' based on severity combined across both the participant's reported functional limitation responses (with 'a lot of difficulty' corresponding to moderate, 'cannot do' as severe) and clinical impairment severity as per the international protocols described above.

Chapter Five *Paper One:* Field testing a draft version of the UNICEF/ Washington Group Module on child functioning and disability. Background, methodology and preliminary findings from Cameroon and India

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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?	Alter, European Journal of Disability Research		
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If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

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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)	

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Short Report

Field testing a draft version of the UNICEF/Washington Group Module on child functioning and disability. Background, methodology and preliminary findings from Cameroon and India

Test de la version provisoire du Module UNICEF/Washington Group sur le fonctionnement et le handicap des enfants. Contexte, méthodologie et premiers résultats au Cameroun et en Inde

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ABSTRACT

Background. – Global child disability data are generally non-comparable, comprising different tools, methodologies and disability definitions. UNICEF and The Washington Group on Disability Statistics (WG) have developed a new tool on child functioning and disability to address this need.
Aims. – The aim of this paper is to describe the development of the new module, and to present an independent field test of the draft module in two contrasting settings.
Methods. – UNICEF and the WG developed a parent-reported survey module to identify children aged 2–17 years with functional

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difficulties in population-based surveys through: review of existing documentation, consultation with experts and cognitive testing. A field test of the draft module was undertaken in Cameroon and India within a population-based survey. Functional limitation in each of 14 domains was scored on a scale comprising "no difficulty", "some difficulty", "a lot of difficulty" and "cannot do".
Results. – In all, 1713 children in Cameroon and 1101 children in India were assessed. Sixty-four percent of children in Cameroon and 35% of children in India were reported to have at least some difficulty in one or more domain. The proportion reported to have either "a lot of difficulty" or "cannot do" was 9% in Cameroon and 4% in India. There were no significant differences in reported functional difficulties by sex but children aged 2–4 were reported to have fewer functional difficulties of any kind compared with older children in both countries.
Conclusion. – Comparable estimates were generated between the two countries, providing an initial overview of the tool's outputs. The continued development of this standardised questionnaire for the collection of robust and reliable data on child disability is essential.

RÉSUMÉ

Mots clés :
Enfants handicapés
Le fonctionnement
Essais sur le terrain

Contexte. – Les données globales sur les enfants handicapés sont difficiles à comparer étant donnée la variété des outils, des méthodologies et des définitions du handicap utilisées. L'UNICEF et le Washington Group (WG) ont développé un nouvel outil pour documenter le fonctionnement et le handicap de l'enfant.
Objectifs. – L'objectif de cette note de recherché vise à décrire le développement de ce nouvel outil et à présenter un test du module provisoire qui a été fait de manière indépendante sur deux terrains différents.
Méthodes. – L'UNICEF et le WG ont développé pour l'enquête un module dans lequel des parents sont interrogés afin d'identifier les enfants âgés de 2 à 17 ans ayant des difficultés fonctionnelles dans les enquêtes en population : examen de la documentation existante, consultation d'experts et tests cognitifs. Le module provisoire a été testé sur le terrain au Cameroun et en Inde dans des enquêtes en population. Les limitations fonctionnelles dans chacun des 14 domaines ont été mesurées avec une échelle allant de « aucune difficulté », « quelques difficultés », « beaucoup de difficultés » à « ne peux pas faire ».
Résultats. – Au total, 1713 enfants ont été évalués au Cameroun et 1101 en Inde à partir de ce module. Soixante-quatre pour cent des enfants au Cameroun et 35 % des enfants en Inde ont rapporté avoir au moins quelques difficultés dans un ou plusieurs domaines. La proportion d'enfants ayant déclaré « beaucoup de difficultés » ou « ne peux pas faire » était de 9 % au Cameroun et de 4 % en Inde. Il n'y avait pas de différences significatives selon le sexe dans les difficultés fonctionnelles déclarées mais les enfants âgés de 2 à 4 ans ont déclaré moins de difficultés fonctionnelles de manière générale par rapport aux enfants plus âgés dans les deux pays.
Conclusion. – Des estimations comparables ont été produites dans les deux pays, fournissant un premier aperçu des potentialités

de l'outil. La poursuite du développement de ce questionnaire standardisé pour collecter des données robustes et fiables sur le handicap de l'enfant est essentielle.

1. Introduction: measuring child disability

Global, national and sub-national population-based data on child disability have historically differed in methodology and rigour, forestalling comparison between countries and over time. A recent global review of child disability datasets by Cappa, Petrowski, & Njelesani (2015) summarised the heterogeneity of available data, much of which predated or otherwise dissented from the prevailing bio-psycho-social conceptualisation of disability as per the International Classification of Disability, Functioning and Health (ICF) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Cappa et al., 2015; The United Nations, 2006; World Health Organization, 2001).

The most frequently cited tool for child disability measurement in population-based data collection efforts is the Ten Questions (TQ) Tool for children aged 2–9 years, used or adapted in a handful of studies of childhood disability in various Low- and Middle-Income Countries (LMICs), and integrated into the third round of the United Nations Children's Fund (UNICEF) Multiple Indicator Cluster Survey Guidelines (Couper, 2002; Hartley & Wirz, 2002; Khan et al., 2009; Muga, 2003; UNICEF, 2008). The TQ documents caregiver-reported health conditions, impairments and activity limitations experienced by children, but has recognised limitations including dichotomous response options, validation only amongst younger children, and low sensitivity for specific impairments (Durkin, Hasan, & Hasan, 1995). Alternative caregiver-reported tools for children have also been developed, including the Rapid Assessment of Disability (RAD) child module and the World Health Organisation Disability Assessment Schedule (WHODAS 2.0) child module, but these have not been validated or widely used (Centre for Eye Research Australia and Nossal Institute for Global Health, 2013; Scorza et al., 2013).

Assessment of disability in children is particularly complicated given the continuum of development experienced throughout childhood. Whilst progression against developmental milestones has been shown to significantly predict developmental outcome in a number of settings, cultural variation can lead to low transferability of milestone-based tools, the majority of which were not developed in LMICs (Brothers, Glascoe, & Robertshaw, 2008; Scherzer, Chhagan, Kauchali, & Susser, 2012).

The dearth of quality evidence on the prevalence and spectrum of child disability reflective of the prevailing framework curtails efforts to advocate, monitor and evaluate disability-inclusive policy and programmes, particularly in the emerging post 2015 agenda. Advancing a consistent definition of disability for both data collection and data disaggregation is therefore urgent.

This paper has two aims:

- to describe the development of a new survey module by UNICEF and the Washington Group on Disability Statistics (commonly known as the Washington Group) to meet this need;
- to present the results of a field test of the draft version of this module in Cameroon and India, comparing findings across the two sites.

2. Development of the UNICEF/Washington Group Extended Set on child functioning and disability

Responding to the lack of agreed tools and methodologies for the assessment of child disability, UNICEF and the Washington Group have developed a parent-reported survey module to identify children with functional difficulties in population-based surveys.

The UNCRPD definition of disability was operationalized in the design of the module, and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) was selected as a conceptual framework for question development (World Health Organization, 2007).

The specific purpose of the module is to identify children with functional difficulties that may place them at a greater risk of experiencing limited participation than children without functional difficulties, as a proxy for equalization of opportunity.

Existing documentation relating to the measurement of childhood disability was collated and analysed to determine appropriate ICF-CY domains for inclusion (Cappa et al., 2015). Extensive consultations with international specialists in child development (paediatricians, developmental psychologists, speech therapists etc.) were also undertaken to further refine the draft question set.

The module focuses on children aged 2–17. Whilst the importance of early detection and intervention for children with functional difficulties is recognised, below the age of two the development process is rapid and varied, can be subjective and culturally influenced, and may not represent the presence of functional limitation. Age-range specific variations of some questions were developed to account for the continuum of development across childhood.

Following established Washington Group validation procedures, the module underwent extensive cognitive testing between 2012 and 2014 in India, Belize, Oman, Montenegro, and USA (Madans et al., 2004; Crialesi, De Palma, & Loeb, 2015).

The remainder of this paper presents the results of an independent field test of a draft version of the module as part of two surveys of disability in Cameroon (2013) and India (2014). Since its application in this research, the module has undergone several modifications and revisions.

3. Methods

Two population-based surveys of disability including people of all ages were conducted by the International Centre for Evidence in Disability (ICED) at the London School of Hygiene & Tropical Medicine, in Cameroon (2013) and India (2014). Representatives from both UNICEF and the Washington Group participated in the study's advisory committee but were not members of the study team. The aim of the overall study was to develop a comprehensive population-based disability survey methodology (using both self-reported functional limitations and objective tools to measure clinical impairment) compatible with the ICF, and to explore the relationship between different components of disability within this framework.

The remainder of this manuscript focuses on the use and results of the draft UNICEF/Washington Group module on child functioning and disability to determine reported functional limitations in children aged 2–17 years.

The sample-size was calculated using a conservative expected all-age prevalence of moderate/severe hearing, vision and physical impairment of 4% (World Health Organization, 2011). A minimum all-age sample-size of 4056 per country was calculated, assuming 20% precision, 95% confidence, a design effect of 1.5 and 20% non-response.

We used a two-stage sampling procedure; fifty-one clusters of eighty people were selected using probability-proportionate-to-size sampling, using the most recent census for the sampling frame. Within clusters, households were selected using compact segment sampling. Each enumerated child aged 2–17 was assessed using a draft version of the UNICEF/Washington Group module on child functioning and disability.

In this draft version, 14 functional domains (D1-D14), separated into "Basic Function" and "Complex Function, Emotion and Participation" domains, were assessed. Domains are coded as follows in Table 1.

Age-relevant variations were included for some domains (e.g. playing) and certain domains were included only for children aged 5–17. The draft version of the module used in the study is available upon request.

Functional limitation in 12 of the 14 domains were reported on a 4-point scale: "no difficulty", "some difficulty", "a lot of difficulty" and "cannot do at all". The response categories for the remaining two domains (controlling behaviour and anxiety/sadness) were "the same or less", "more" and "a lot more".

Table 1
Module domains.

Basic function domains		Complex function, emotion and participation domains	
D1	Seeing	D9	Feeling worried/sad[a]
D2	Hearing	D10	Controlling behaviour
D3	Walking	D11	Completing a task[a]
D4	Self-care[a]	D12	Accepting change[a]
D5	Understanding	D13	Getting along with other children[a]
D6	Being understood	D14	Playing
D7	Learning		
D8	Remembering[a]		

[a] Children 5–17 only.

Usage of glasses and hearing aids were also included. To standardize proxy-respondent responses to generally accepted stages of child development, where appropriate, questions were prefaced with the clause "compared with children of the same age. . .".

Parents or adult primary caregivers reported for children under the age of 9 or unable to communicate independently. Children aged 9 and above were interviewed directly where feasible and appropriate.

In India, a single question "do you consider yourself [age 9–17]/your child [age 2–8] to have a disability?" was included for comparison purposes.

Three survey teams per country received 10 days training on disability awareness, project protocols and tools, ethics and practice interviewing. Teams consisted of 3 clinical team members, 5 field assistants, and 2 interviewers. Field assistants in each team were responsible for completing the UNICEF/Washington Group module.

Ethical Approval for the study was granted by:

- the London School of Hygiene and Tropical Medicine;
- Cameroon National Ethics Committee for Research in Human Health;
- Cameroon Baptist Convention Health Board Institutional Review Board;
- Public Health Foundation of India Institutional Ethics Committee;
- Government of India Health Ministry Screening Committee.

Basic medicines (vitamins, anti-inflammatories, ear and eye drops) were distributed by clinical team members as needed, and all participants with unmet health needs were referred to relevant and available health, rehabilitation or educational services.

Caregivers of all children aged 2–17 were read an information sheet about the study and given the opportunity to ask questions. If they agreed to participate, written/finger print consent was taken from the caregiver and assent was provided by children aged 9 and above. Caregivers were required to remain present throughout the interview process.

In both settings, the questionnaires were cognitively tested for context relevance and adapted accordingly. The module was translated into Telegu in India and verbally translated into Pigin English in Cameroon, using a phrase sheet of appropriate phonetic translations.

Data was double-entered into Microsoft Access, corrected for inconsistencies between entries using the EpiInfo Data Compare utility and merged in STATA 12.0 for analysis. The svy command was used to derive prevalence estimates with 95% confidence intervals (CI) at different functional thresholds ("no difficulty" in any, "some difficulty" in at least one domain, "some difficulty" in at least two domains, "a lot of difficulty" in at least one domain and "cannot do" in at least one domain), accounting for the cluster sampling design. Domain-specific analyses are reported as "at least some difficulty" and "at least a lot of difficulty", given small numbers. Associations between reported limitations (both aggregate domains and for each specific domain), age group and gender were assessed using a Chi^2 test of association. Pearson's correlation coefficient analysis (r) was computed to assess pairwise relationships between endorsed domains.

Table 2
Cohort descriptors.

	Cameroon			India		
	Male	Female	Total	Male	Female	Total
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (100%)
2–4	166 (19.6)	200 (23.2)	366 (21.4)	113 (19.7)	120 (22.8)	233 (21.2)
5–8	270 (31.8)	237 (27.4)	507 (29.6)	163 (28.4)	140 (26.6)	303 (27.5)
9–12	222 (26.2)	226 (26.2)	448 (26.2)	138 (24.0)	135 (25.7)	273 (24.8)
13–17	191 (22.5)	201 (23.3)	392 (22.9)	161 (28.0)	131 (24.9)	292 (26.5)
Total	849 (100)	864 (100)	1713 (100)	575 (100)	526 (100)	1101 (100)

4. Results

4.1. Overall ressults

Findings use the age grouping 2–4, 5–8, 9–12 and 13–17 years to accommodate age-range specific questions, and are presented as the minimum level of limitation endorsed. "Reported" refers to both caregiver report for children age 2–8 and self-report for children 9–17.

Table 2 presents the study cohort descriptors. A total of 1713 children aged 2–17 were assessed in Cameroon, and 1101 in India. Fifty percent of the study children were male in Cameroon and 52% in India.

Aggregate domain endorsement across all domains and stratified by domain type (basic versus complex) are presented in Table 3. Two thirds of the sample in Cameroon reported at least some difficulty in at least one domain (63.9%, 95% CI 60.0–67.6), compared with one third in India (34.9%, 30.8–39.2). Prevalence declined with increasing reported difficulty in both samples. In Cameroon, 42.0% (38.0–46.0) reported some difficulty in any two domains, 8.9% (7.1–11.2) reported a lot of difficulty in any one domain and 0.7% (0.4–1.2) reported inability to do any one domain. In India 19.8% (16.5–23.6) reported some difficulty in any two domains, 3.5% (2.3–5.1) a lot of difficulty in any one, and 0.9 (0.5–1.7) inability to do any one. This trend repeated when disaggregated by basic versus complex domains in both countries, with higher proportions identified in Cameroon at the level of some difficulty in one, or two domains (basic or complex) than India, but similar, much lower prevalence estimates at the higher levels of difficulty.

Table 3
Aggregate domain endorsement in Cameroon and India.

	Cameroon, *n* = 1713 % (95% CI)	India, *n* = 1101 % (95% CI)
No difficulty in any domain	36.1 (32.4–40.1)	65.1 (60.8–69.2)
All domains		
At least some difficulty in one domain	63.9 (60.0–67.6)	34.9 (30.8–39.2)
At least some difficulty in two domains	42.0 (38.0–46.0)	19.8 (16.5–23.6)
At least a lot of difficulty in one domain	8.9 (7.1–11.2)	3.5 (2.3–5.1)
At least cannot do in one domain	0.7 (0.4–1.2)	0.9 (0.5–1.7)
Basic domains		
At least some difficulty in one domain	43.7 (39.8–47.8)	28.0 (24.1–32.2)
At least some difficulty in two domains	19.7 (17.0–22.7)	12.3 (9.7–15.4)
At least a lot of difficulty in one domain	2.5 (1.8–3.5)	2.0 (1.2–3.4)
At least cannot do in one domain	0.4 (0.1–0.9)	0.7 (0.4–1.4)
Complex domains		
At least some difficulty in one domain	43.1 (39.7–46.5)	17.3 (14.0–21.1)
At least some difficulty in two domains	18.3 (16.1–20.8)	7.1 (5.3–9.4)
At least a lot of difficulty in one domain	7.4 (5.7–9.5)	2.3 (1.5–3.5)
At least cannot do in one domain	0.6 (0.3–1.0)	0.5 (0.2–1.3)

Table 4
Aggregate domain endorsement in Cameroon and India.

	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	p
	n	%	*n*	%	*n*	%	*n*	%		
Cameroon										
No difficulty in any domain	193	52.7	172	33.9	139	31.0	115	29.3	57.7	<0.001
Basic Domains										
At least some difficulty in one domain	101	27.6	207	40.8	229	51.1	213	54.3	68.3	<0.001
At least some difficulty in two domains	40	10.9	79	15.6	118	26.3	101	25.8	44.8	<0.001
At least a lot of difficulty in one domain	7	1.9	13	2.6	11	2.5	12	3.1	1.0	0.8
At least cannot do in one domain	1	0.3	5	1.0	0	0	0	0	8.9	<0.05
Complex domains										
At least some difficulty in one domain	81	22.1	257	50.7	209	46.7	191	48.7	84.9	<0.001
At least some difficulty in two domains	4	1.1	124	24.5	103	23.0	83	21.2	94.0	<0.001
At least a lot of difficulty in one domain	27	7.4	44	8.7	31	6.9	24	6.1	2.3	0.5
At least cannot do in one domain	0	0	8	1.6	1	0.2	1	0.3	12.5	<0.01
India										
No difficulty in any domain	169	72.5	193	63.7	173	63.4	182	62.3	7.3	0.06
Basic domains										
At least some difficulty in one domain	55	23.6	82	27.1	80	29.3	91	31.2	4.0	0.3
At least some difficulty in two domains	25	10.7	46	15.2	33	12.1	31	10.6	3.7	0.3
At least a lot of difficulty in one domain	5	2.2	5	1.7	6	2.2	6	2.1	0.3	1.0
At least cannot do in one domain	4	1.7	1	0.3	1	0.4	2	0.7	4.3	0.2
Complex domains										
At least some difficulty in one domain	22	9.4	59	19.5	53	19.4	56	19.2	12.7	<0.01
At least some difficulty in two domains	4	1.7	25	8.3	21	7.7	28	10.0	13.8	<0.01
At least a lot of difficulty in one domain	6	2.6	7	2.3	6	2.2	6	2.1	0.2	1.0
At least cannot do in one domain	1	0.4	1	0.3	2	0.7	1	0.3	0.7	0.9

Table 4 presents overall endorsement of basic and complex domains disaggregated by age. Children in the youngest age group (2–4) were least likely to have any difficulties in any domains in both countries ($p < 0.001$). In Cameroon, age group was strongly associated with reporting some difficulty in one or more basic or complex domain ($p < 0.001$), but there was no clear trend by age. In India, age group was associated with reporting some difficulty in one or more complex domain ($p < 0.01$) only. Reporting a lot of difficulty or higher in any basic or complex domain was not significantly different by age group in either country. There was no statistical difference by sex in overall endorsement of basic and complex domains in either country (data not shown).

Table 5 presents the overall proportion of children in Cameroon and India reporting at least some difficulty and at least a lot of difficulty by specific domain.

4.2. Results by functional domain in Cameroon

In Cameroon, the most commonly reported limitations in basic domains at the some or greater difficulty level were learning and remembering (20.8% and 28.8% of children 2–17 and 5–17 respectively, Table 5). Common difficulties in other basic functional domains were at least some difficulty hearing (7.6%) or seeing (5.8%).

The most common complex domains in which at least some difficulty was reported were controlling behaviour (23.2% of children 2–17), accepting change (22.6% of children 5–17) and feeling worried/sad (20.0% of children 5–17). Less than 1% of the sample in Cameroon reported a lot of difficulty or higher in any basic domain, with the exception of remembering (1.1% of 5–17 year olds). Amongst complex domains, 3.2% of children 2–17 reported a lot of difficulty or higher controlling their behaviour, 3.4% of children aged 5–17 reported a lot of difficulty or higher with worrying or feeling sad, and 2.0% of children aged 5–17 reported a lot of difficulty or higher in accepting change. Less than 2% reported a lot of difficulty or more in completing tasks (1.6%), playing (0.6%) or getting along with other children. There were no statistically significant differences by sex in any specific domain at any degree of difficulty (data not shown here).

Table 5
Proportion endorsing each domain–Cameroon and India.

	Cameroon				India			
	At least some difficulty		A least a lot of difficulty		At least some difficulty		At least a lot of difficulty	
	n	%	*n*	%	*n*	%	*n*	%
Basic domains								
2–17								
Seeing	99	5.8	6	0.4	46	4.2	3	0.3
Hearing	130	7.6	6	0.4	38	3.5	5	0.5
Walking	93	5.4	13	0.8	39	3.5	9	0.8
Understanding	86	5.0	6	0.4	84	7.6	10	0.9
Being understood	83	4.9	7	0.4	77	7.0	8	0.7
Learning	357	20.8	11	0.6	125	11.4	10	0.9
5–17[a]								
Remembering	388	28.8	15	1.1	151	17.4	7	0.8
Self-care	79	5.9	4	0.3	33	3.8	6	0.7
Basic domains								
2–17								
Controlling behaviour[b]	397	23.2	55	3.2	118	10.7	11	1.0
Playing	69	4.0	11	0.6	54	4.9	12	1.1
5–17[a]								
Feeling worried/sad[b]	270	20.0	46	3.4	59	6.8	7	0.8
Completing task	253	18.8	22	1.6	71	8.2	8	1.0
Accepting change	305	22.6	27	2.0	49	5.6	9	1.0
Getting along with other children	59	4.4	5	0.4	39	4.5	9	1.0

[a] Question valid age 5–17 only, denominator reflects this.
[b] Maximum option is "a lot more", not "cannot" for this question.

Table 6 (overleaf) stratifies the proportion of children in Cameroon and India reporting at least some difficulty in each basic and complex domain by age group. In Cameroon, reporting at least some difficulty in seeing and hearing (2–17 years), and remembering and feeling worried/sad (5–17 years) were positively associated with age group ($p < 0.001$–$p < 0.01$), whilst being understood (2–17 years), self-care and completing a task (both age 5–17) were negatively associated ($p < 0.01$). Walking, learning and playing (all 2–17 years) were all associated with age ($p < 0.05$), but with no directional trend. There were no significant differences by age in the proportions of children reported to experience a lot of difficulty or inability to complete any basic domain or complex domains, although cell sizes were very small (data not shown here).

4.3. Results by functional domain in India

Basic domains related to cognition were the most frequently reported in India (some or greater difficulty in understanding: 7.6%, being understood: 7.0%, learning: 11.4% and remembering: 17.4%), whilst less than five percent reported some or greater difficulty in the remaining basic domains (seeing: 4.2%, hearing: 3.5%, walking: 3.5% and self-care: 3.8%), as shown in Table 5. Commonly reported complex domains included 10.7% of children aged 2–17 reporting at least some difficulty in controlling behaviour, and amongst those aged 5–17, 8.2% reporting at least some difficulty completing tasks and 6.8% feeling worried or sad. Less than two percent of children reported a lot of difficulty or greater in any basic or complex domain.

There were generally no clear differences by sex in reporting some or greater difficulty in different domains (data not shown here), and fewer associations between specific domains and age group than in Cameroon (Table 6). Some or greater difficulty understanding (2–17) or with self-care (5–17) were negatively associated with age ($p < 0.05$), whilst seeing, walking and learning (all 2–17) were associated but showed no trend.

Table 6
Proportion endorsing at least Some Difficulty in Cameroon and India.

	Cameroon										India									
	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	p	2 to 4		5 to 8		9 to 12		13 to 17		χ^2	p
	n	%	n	%	n	%	n	%			n	%	n	%	n	%	n	%		
Basic domains																				
2–17																				
Seeing	6	1.6	17	3.4	33	7.4	43	11.0	38.5	<0.001	3	1.3	3	1.0	15	5.5	25	8.6	27.8	<0.001
Hearing	7	1.9	28	5.5	45	10.0	50	12.8	38.7	<0.001	3	1.3	12	4.0	14	5.1	9	3.1	5.9	0.1
Walking	17	4.6	19	3.8	24	5.4	33	8.4	10.1	<0.05	15	6.4	4	1.3	8	2.9	12	4.1	10.7	<0.05
Understanding	28	7.7	23	4.5	21	4.7	14	3.6	7.4	0.06	26	11.2	26	8.6	17	6.2	15	5.1	7.8	<0.05
Being understood	30	8.2	22	4.3	17	3.8	14	3.6	11.7	<0.01	23	9.9	23	7.6	16	5.9	15	5.1	5.2	0.2
Learning	69	18.9	84	16.6	115	25.7	89	22.7	13.6	<0.01	39	16.7	34	11.2	23	8.4	29	9.9	9.6	<0.05
5–17 only[a]																				
Remembering	–	–	112	22.1	140	31.3	136	34.7	19.1	<0.001	–	–	53	17.5	46	16.8	52	17.8	0.1	1.0
Self-care	–	–	60	11.8	16	3.6	3	0.8	55.5	<0.001	–	–	19	6.3	8	2.9	6	2.1	8.1	<0.05
Complex domains																				
2–17																				
Controlling behaviour	92	25.1	118	23.3	108	24.1	79	20.2	3.0	0.4	16	6.9	32	10.6	33	12.1	37	12.7	5.3	0.2
Playing	15	4.1	21	4.1	9	2.0	24	6.1	9.2	<0.05	14	6.0	12	4.0	14	5.1	14	4.8	1.2	0.7
5–17 only[a]																				
Feeling worried/sad[b]	–	–	84	16.6	85	19.0	101	25.8	12.1	<0.01	–	–	18	6.0	18	6.6	23	7.9	0.9	0.6
Completing task	–	–	132	26.0	72	16.1	49	12.5	29.8	<0.001	–	–	26	8.6	18	6.6	27	9.2	1.4	0.5
Accepting change	–	–	122	24.1	102	22.8	81	20.7	1.5	0.5	–	–	20	6.6	9	3.3	20	6.8	4.1	0.1
Getting along with other children	–	–	24	4.7	15	3.3	20	5.1	1.8	0.4	–	–	13	4.3	11	4.0	15	5.1	0.4	0.8

[a] Questions valid age 5-17 only, denominator reflects this.
[b] Maximum option is "a lot more", not "cannot" for this question.

Table 7
Single question responses in India.

	n	Yes		No	
		n	%	*n*	%
No difficulty in any domain	717	4	0.6	713	99.4
Some or greater difficulty in one or more domain	384	23	6.0	361	94.0
A lot or greater difficulty in one or more domain	38	17	44.7	21	55.3
Total	1713	27	2.5	1074	97.6

4.4. Relationship between endorsed domains

Appendix 1 presents the pairwise correlation matrix between domains for Cameroon endorsed at the level of some difficulty or higher. No strong, significant relationships ($r > 0.7$, $p < 0.05$) were identified between any two domains. A moderate positive relationship was identified between understanding and being understood ($r = 0.55$, $p < 0.05$). Weak but significant positive relationships were also identified between remembering and learning, and between completion of a task and accepting change (both $r = 0.36$, $p < 0.05$).

In India, the only strong and statistically significant pairwise relationship at the level of some or greater difficulty was between understanding and being understood ($r = 0.77$, $p < 0.05$), presented in Appendix 2. Four pairs demonstrated moderate positive relationships, and 20 pairs demonstrated weak but positive relationships. In particular, at least some difficulty playing was significantly associated (all $p < 0.05$) with at least some difficulty in the domains of self-care, understanding, being understood, learning, worrying/feeling sad, controlling behaviour, completing tasks, accepting change and getting along with others. Similarly, at least some difficulty in getting along with others was significantly associated with at least some difficulty in self-care, being understood, worrying/feeling sad, completing tasks and accepting change.

4.5. Single question on disability

In the Indian sample, 2.5% answered "yes" to the question "do you consider yourself [age 9–17]/your child [age 2–8] to have a disability" (Table 7). Less than one percent of those who did not report any difficulties in any domain answered affirmatively, compared with 6% of those who reported some or greater difficulty in any domain, and 44.7% of those who reported a lot or greater difficulty in any domain.

5. Discussion

5.1. Aggregate domain endorsement

Two thirds of the sample in Cameroon reported at least some difficulty in at least one domain, compared with one third in India. Just under half of the sample reported some difficulty in any basic (43.7%) or complex (43.1%) domain in Cameroon, compared with 28.0% and 17.3% respectively in India. However, at the higher threshold of a lot of difficulty or greater, less than three percent reported difficulties in any basic domain in either country (2.5% in Cameroon and 2.0% in India), and less than ten percent in any complex domain (7.4% and 2.3% respectively). At the highest level cannot do, less than one percent in either country reported difficulties in either basic or complex domains. Gender does not appear to be related to functional limitations as endorsed in this study in either country. However, children in the youngest age group (2–4) were least likely to report any difficulties in any domain in either country, albeit with no discernible trend at the aggregate level.

As already discussed, there are limited available data with which to compare these findings. The Cameroon MICS (2006) estimated a prevalence of 13.9% amongst children 2–9 in North West Cameroon using the Ten Questions (TQ) tool (Institut National de la Statistique, 2012). The tool was used in the study without a second-stage assessment, which is estimated to lead to 300% overestimation of serious disability (Durkin et al., 1995). Data from the Indian Census (2011) estimates disability amongst children 0–9 in India of 1.6% at the national level (Government of India Ministry of Home Affairs, 2011). The census used a disability screener ("Is this person mentally/physically disabled") followed by a list of 8 types of disability; a method previously shown to underestimate the proportion of people with disabilities (Mont, 2007; Office of the Registrar General and Census Commissioner, 2013).

The large variation between the all-age proportion of children reported to have "some" difficulty between Cameroon and India may suggest different cultural interpretations of the term, reinforcing the importance of contextual translation. In addition, lowest agreement between countries was found in the 9–12 age group, who were the youngest group to self-report. This may indicate that this age group is not consistent in self-reporting, adding to debate on proxy versus self-report in children.

The all-age aggregate domain similarity between countries at the higher thresholds of "a lot of difficulty" and "cannot do" may suggest that whilst "some difficulty" may be reported in relation to regular variation in the child's general development, this is distinct to reporting a perceived substantial limitation at the level of "a lot of difficulty" or "cannot do".

5.2. Endorsement by domain

Domain-specific analyses provide further insight. In both countries, reporting some difficulty in basic domains related to cognition (learning, remembering, understanding, being understood) was higher (up to 30%) than sensory or mobility domains, or self-care (less than ten percent) in both countries. Some or greater difficulty in complex domains were generally endorsed more frequently than basic domains, ranging between 4% and 24% in Cameroon, and 5% and 11% in India. Most commonly these were controlling behaviour, accepting change and feeling worried or sad. It will be important to further probe whether these responses are related to functional limitation or natural variations in child development appropriate to age.

No individual domains (basic or complex) in either country were endorsed at the level of a lot or greater difficulty by more than five percent of the respective samples, and the majority were endorsed by less than one percent.

5.3. Endorsement by age group

Further breakdown of domain endorsement by age group shows numerous directional and non-directional associations between reporting some or greater difficulty and age group.

A significantly higher proportion of young children aged 2–4 were reported to experience at least some difficulties in domains related to milestones of early childhood development (walking, understanding, being understood, learning) than older children. Gladstone et al. (2010) examined the reliability in Malawi of several tools developed in High Income settings to assess early childhood development. The study found that items related to gross motor or language development milestones were generally reliable, but items related to social skills showed poor reliability in a Malawian setting (Gladstone et al., 2010).

Older children were also more likely to report "some" difficulties in seeing, hearing and remembering than younger children (whose caregivers reported on their behalf) in Cameroon. Similarly, older children were also more likely to report some difficulty seeing in India. Previous studies have shown that caregivers may experience difficulty identifying sensory impairments in children at an early age, which may account for the comparatively lower proportions of parental-reported younger children reported to experience sensory limitations (Omondi, Ogol, Otieno, & Macharia, 2007; Rahi, Cumberland, & Peckham, 2010).

Further, the reliance on proxy report adds a second dimension of complexity given potential for mis-reporting by caregivers (Eiser & Morse, 2001). Older children (who self-reported) were significantly more likely to report feeling worried/sad than younger children (reported for by proxy) in Cameroon. A systematic review of the relationship between parental and child self-reported health-related quality of life (HRQoL) found greater agreement on "observable" functioning such as physical functioning and symptoms of somatic distress, and lower agreement in domains related to emotional or social HRQoL issues (Eiser & Morse, 2001). Further work is needed to validate whether parental report on emotional and behavioural domains are acceptably in agreement with the perspective of the child.

5.4. Pairwise Domain Relationships

Limited pairwise correlations were identified in either country. Namely, with the exception of a strong and predictable correlation between at least some difficulty in both understanding and being understood in India (and none in Cameroon), there were no strong statistically significant pairwise relationships between domains to justify combination algorithms of reporting some difficulty in two or more domains as a threshold for prevalence estimations.

5.5. Comparison with a Single Question

The inclusion of a single question on disability perception in India further emphasises the need for the UNICEF/Washington Group module. Less than 2.5% of the overall sample responded affirmatively to this question, including less than half of those who reported a lot of difficulty or greater in one or more domain. This shows that not only does a single question lead to under report of significant limitations in functioning in children, but also the clear difference between reporting some difficulty in functioning (6% of who also responded yes to the singe question) and a lot of difficulty/inability to complete (44.7%).

5.6. Strengths and Limitations

The study sample in Cameroon and India of a combined 2814 children aged 2–17 represents one of the first field tests of the draft UNICEF/Washington Group module on child functioning and disability. This data is urgently needed to respond to calls for a consistent method for child disability data collection and disaggregation.

A potential limitation of the study is that all children aged 9 and above who were able to communicate independently were interviewed directly in the presence of a primary caregiver, whist children aged 2–8 or unable to communicate independently were interviewed via adult proxy report. Consequently, the findings are part parental-reported and part self-reported by children, which limit comparability between age groups.

In addition, further comprehensive field tests by UNICEF and the Washington Group, including comparison of findings against established tools, determination of response distributions, module behaviour tests (e.g. non-response rates and sample-size calculations) were completed in mid-2015. These results and the final version of the module will be presented in a separate publication, and may not be fully reflected in the results presented here.

5.7. Implications for further research

The very high and moderately high proportions of children reported to have at least "some" difficulty in one or more domain in Cameroon and India respectively warrants further investigation, to identify whether the threshold accurately identifies functional limitation or generates false positives. In particular, future research should clarify whether this issue was compounded by translation errors in Cameroon, or whether this is a common finding. The issue is further complicated by the use of a proxy respondent, given previous findings on the capacity of proxies to gauge limitations in

emotional or social domains. Field testing of the final module will include probing questions to address the nuances of a parental report of "some" difficulty, so as to address this issue. Additionally, a forthcoming research study conducted by the Question Design Research Laboratory (QDRL) at the US National Center for Health Statistics (NCHS) will compare self and proxy respondents to the UNICEF/Washington Group module on child functioning and disability for a sample of youth aged 15-17 years of age and their parent.

The final round of field testing will further progress the capacity of the UNICEF/Washington Group module to adequately and accurately identify children at risk of experiencing limited participation and consequently the availability of appropriate methodologies for generating child disability statistics.

6. Conclusions

During this field test of the draft UNICEF/Washington Group module on child functioning and disability, comparable overall estimates were generated at the "a lot of difficulty" and "cannot do" thresholds across the two study settings, although an absence of similar prevailing studies prevents us from validating or rejecting these estimates. It is hoped that this endeavour to produce a standardised questionnaire will greatly advance the collection of child disability data statistics in providing a robust and reliable methodology for the determination of disability status among children in survey settings.

Disclosure of interest

The authors declare that they have no competing interest.

Appendix 1. Relationship between domains in India–Pearson's Correlation Coefficient (*r*)

D1	*r*	1													
	p														
D2	*r*	0.0849[a]	1												
	p	0.0048													
D3	*r*	0.1319[a]	0.0984[a]	1											
	p	0	0.0011												
D4	*r*	0.1230[a]	0.1127[a]	0.1969[a]	1										
	p	0	0.0002	0											
D5	*r*	0.0939[a]	0.0956[a]	0.2781[a]	0.2705[a]	1									
	p	0.0018	0.0015	0	0										
D6	*r*	0.0851[a]	0.0847[a]	0.2557[a]	0.2651[a]	0.7663[a]	1								
	p	0.0047	0.0049	0	0	0									
D7	*r*	0.0684[a]	0.0421	0.1947[a]	0.2225[a]	0.4687[a]	0.4182[a]	1							
	p	0.0233	0.1625	0	0	0	0								
D8	*r*	0.1015[a]	0.0982[a]	0.0807[a]	0.2551[a]	0.2136[a]	0.2220[a]	0.3317[a]	1						
	p	0.0007	0.0011	0.0074	0	0	0	0							
D9	*r*	0.0914[a]	0.0655[a]	0.1508[a]	0.2420[a]	0.2203[a]	0.2194[a]	0.2200[a]	0.2803[a]	1					
	p	0.0024	0.0298	0	0	0	0	0	0						
D10	*r*	0.1331[a]	0.0632[a]	0.2195[a]	0.2146[a]	0.2875[a]	0.2849[a]	0.2647[a]	0.3228[a]	0.2435[a]	1				
	p	0	0.0361	0	0	0	0	0	0	0					
D11	*r*	0.0745[a]	0.0719[a]	0.0897[a]	0.2792[a]	0.2728[a]	0.3050[a]	0.2441[a]	0.2931[a]	0.2495[a]	0.4709[a]	1			
	p	0.0134	0.017	0.0029	0	0	0	0	0	0	0				
D12	*r*	0.1090[a]	0.0316	0.0778[a]	0.2979[a]	0.2366[a]	0.2862[a]	0.1727[a]	0.2725[a]	0.3202[a]	0.3951[a]	0.5889[a]	1		
	p	0.0003	0.2951	0.0098	0	0	0	0	0	0	0	0			
D13	*r*	0.1319[a]	0.0445	0.0962[a]	0.3409[a]	0.2966[a]	0.3135[a]	0.2567[a]	0.2950[a]	0.4781[a]	0.2989[a]	0.4098[a]	0.5067[a]	1	
	p	0	0.1399	0.0014	0	0	0	0	0	0	0	0	0		
D14	*r*	0.0787[a]	0.1183[a]	0.2750[a]	0.3054[a]	0.4100[a]	0.3665[a]	0.3297[a]	0.2273[a]	0.3755[a]	0.3020[a]	0.3513[a]	0.4201[a]	0.6163[a]	1
	p	0.009	0.0001	0	0	0	0	0	0	0	0	0	0	0	
		D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12	D13	D14

Key: D1 Seeing, D2 Hearing, D3 Walking, D4 Self-Care, D5 Understanding, D6 Being Understood, D7 Learning, D8 Remembering, D9 Feeling worried/sad, D10 Controlling Behaviour, D11 Completing a Task, D12 Accepting Change, D13 Getting along with other children, D14 Playing.

[a] Indicate that r is statistically significant at the 5% significance level.

Appendix 2. Relationship between domains in Cameroon–Pearson's Correlation Coefficient (*r*)

D1	*r*	1													
	p														
D2	*r*	0.0896[a]	1												
	p	0.0002													
D3	*r*	0.029	0.0675[a]	1											
	p	0.2305	0.0052												
D4	*r*	-0.0187	0.0421	0.0824[a]	1										
	p	0.4399	0.0816	0.0006											
D5	*r*	0.0003	0.0855[a]	0.0393	0.1151[a]	1									
	p	0.9887	0.0004	0.104	0										
D6	*r*	0.014	0.0996[a]	0.0419	0.1059[a]	0.5457[a]	1								
	p	0.5621	0	0.0828	0	0									
D7	*r*	0.0084	0.1243[a]	0.0800[a]	0.0791[a]	0.2309[a]	0.1921[a]	1							
	p	0.7275	0	0.0009	0.0011	0	0								
D8	*r*	0.0572[a]	0.1451[a]	0.0673[a]	0.1137[a]	0.1055[a]	0.0987[a]	0.3610[a]	1						
	p	0.0178	0	0.0053	0	0	0	0							
D9	*r*	0.0835[a]	0.0740[a]	0.0646[a]	0.1020[a]	0.0679[a]	0.0652[a]	0.1143[a]	0.2369[a]	1					
	p	0.0005	0.0022	0.0075	0	0.0049	0.007	0	0						
D10	*r*	0.0478[a]	0.0359	0.0088	0.0573[a]	0.1018[a]	0.1080[a]	0.1508[a]	0.1457[a]	0.1010[a]	1				
	p	0.0481	0.1375	0.7149	0.0176	0	0	0	0	0					
D11	*r*	-0.0255	0.005	0.0382	0.1752[a]	0.0625[a]	0.0517[a]	0.1388[a]	0.1796[a]	0.0795[a]	0.1769[a]	1			
	p	0.2908	0.8372	0.1137	0	0.0096	0.0325	0	0	0.001	0				
D12	*r*	0.0221	0.0222	0.0366	0.1960[a]	0.0747[a]	0.0087	0.2045[a]	0.2658[a]	0.2226[a]	0.2326[a]	0.3611[a]	1		
	p	0.3616	0.3584	0.1295	0	0.002	0.7195	0	0	0	0	0			
D13	*r*	0.0493[a]	0.0184	0.0819[a]	0.0958[a]	0.1325[a]	0.1065[a]	0.1080[a]	0.1272[a]	0.1102[a]	0.1390[a]	0.1109[a]	0.1966[a]	1	
	p	0.0415	0.4465	0.0007	0.0001	0	0	0	0	0	0	0	0		
D14	*r*	0.0511[a]	0.0086	0.0164	0.0824[a]	0.1025[a]	0.1474[a]	0.1434[a]	0.0736[a]	0.0487[a]	0.1267[a]	0.1239[a]	0.1220[a]	0.2544[a]	1
	p	0.0346	0.7233	0.4968	0.0006	0	0	0	0.0023	0.0439	0	0	0	0	
		D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12	D13	D14

Key: D1 Seeing, D2 Hearing, D3 Walking, D4 Self-Care, D5 Understanding, D6 Being Understood, D7 Learning, D8 Remembering, D9 Feeling worried/sad, D10 Controlling Behaviour, D11 Completing a Task, D12 Accepting Change, D13 Getting along with other children, D14 Playing.

[a] Indicates that r is statistically significant at the 5% significance level.

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Chapter Six *Paper Two:* Measuring Disability in Population-based Surveys: The Interrelationship between Clinical Impairments and Reported Functional Limitations in Cameroon and India

RESEARCH PAPER COVER SHEET

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SECTION A – Student Details

Student	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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		
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RESEARCH ARTICLE

Measuring Disability in Population Based Surveys: The Interrelationship between Clinical Impairments and Reported Functional Limitations in Cameroon and India

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Abstract

Purpose

To investigate the relationship between two distinct measures of disability: self-reported functional limitations and objectively-screened clinical impairments.

Methods

We undertook an all age population-based survey of disability in two areas: North-West Cameroon (August/October 2013) and Telangana State, India (Feb/April 2014). Participants were selected for inclusion via two-stage cluster randomised sampling (probability proportionate to size cluster selection and compact segment sampling within clusters). Disability was defined as the presence of self-reported functional limitations across eight domains, or presence of moderate or greater clinical impairments. Clinical impairment screening comprised of visual acuity testing for vision impairment, pure tone audiometry for hearing impairment, musculoskeletal functioning assessment for musculoskeletal impairment, reported seizure history for epilepsy and reported symptoms of clinical depression (depression adults only). Information was collected using structured questionnaires, observations and examinations.

Results

Self-reported disability prevalence was 5.9% (95% CI 4.7–7.4) and 7.5% (5.9–9.4) in Cameroon and India respectively. The prevalence of moderate or greater clinical impairments in the same populations were 8.4% (7.5–9.4) in Cameroon and 10.5% (9.4–11.7) in India. Overall disability prevalence (self-report and/or screened positive to a moderate or greater clinical impairment) was 10.5% in Cameroon and 12.2% in India, with limited overlap between the

data collection and analysis, decision to publish, or preparation of the manuscript.

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sub-populations identified using the two types of tools. 33% of participants in Cameroon identified to have a disability, and 45% in India, both reported functional limitations and screened positive to objectively-screened impairments, whilst the remainder were identified via one or other tool only. A large proportion of people with moderate or severe clinical impairments did not self-report functional difficulties despite reporting participation restrictions.

Conclusion

Tools to assess reported functional limitation alone are insufficient to identify all persons with participation restrictions and moderate or severe clinical impairments. A self-reported functional limitation tool followed by clinical screening of all those who report any level of difficulty would identify 94% of people with disabilities in Cameroon and 95% in India, meeting the study criteria.

Introduction

1.1 Conceptualising disability

The conceptualisation of disability is complex and has evolved over time. Initially, disability was viewed as a purely medical phenomenon determined by an individual having an impairment in body functioning or structure (e.g. the presence of mobility or visual impairments) [1]. Later, the Social Model framed disability as resulting from external restrictions placed by society on people with impairments [2], for instance, through inaccessible buildings reducing the options for people with physical impairments to work. The prevailing framework is the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organisation (WHO) in 2001 [3–7]. The ICF (Fig 1) is considered a *bio-psycho-social* model of disability, which refers to dysfunctioning in one of three interlinked levels–impairments in body function or structure, activity limitations, or participation restrictions–and is the result of an interaction between a health condition and contextual factors.

For example, the disease poliomyelitis (health condition) may affect leg muscle weakness (body function and structure) limiting the individual's ability to walk (activities) and thus attend school (participation restrictions). This "dysfunctioning" can be mediated by environmental factors (e.g. assistive devices) and personal factors (e.g. family support).

1.2 Approaches to measuring disability within the ICF

Disability data based on the ICF are crucial for appropriate service-planning and evidence-based advocacy. Despite this, few robust population-level disability surveys exist globally. Amongst those that do, non-comparable and non-comprehensive methodologies are used [8].

There are three broad measurement approaches in disability. The most rapid is direct questioning, e.g. "Do you consider yourself to have a disability?" [9, 10]. This leads to substantial under-reporting, due to stigma and cultural perceptions of disability, and is not considered adequate [1, 11].

A second approach is to ask people to report whether they experience activity limitations in core domains of function e.g. whether they have difficulties in seeing or hearing [12, 13]. This approach focuses on the "activities" component of the ICF. The method recognises the spectrum of functional limitations people with the same impairment may have and maximises the information that can be garnered at low cost. In addition, the use of scaled response options allows estimation of the continuum of functional difficulties in the population [14, 15].

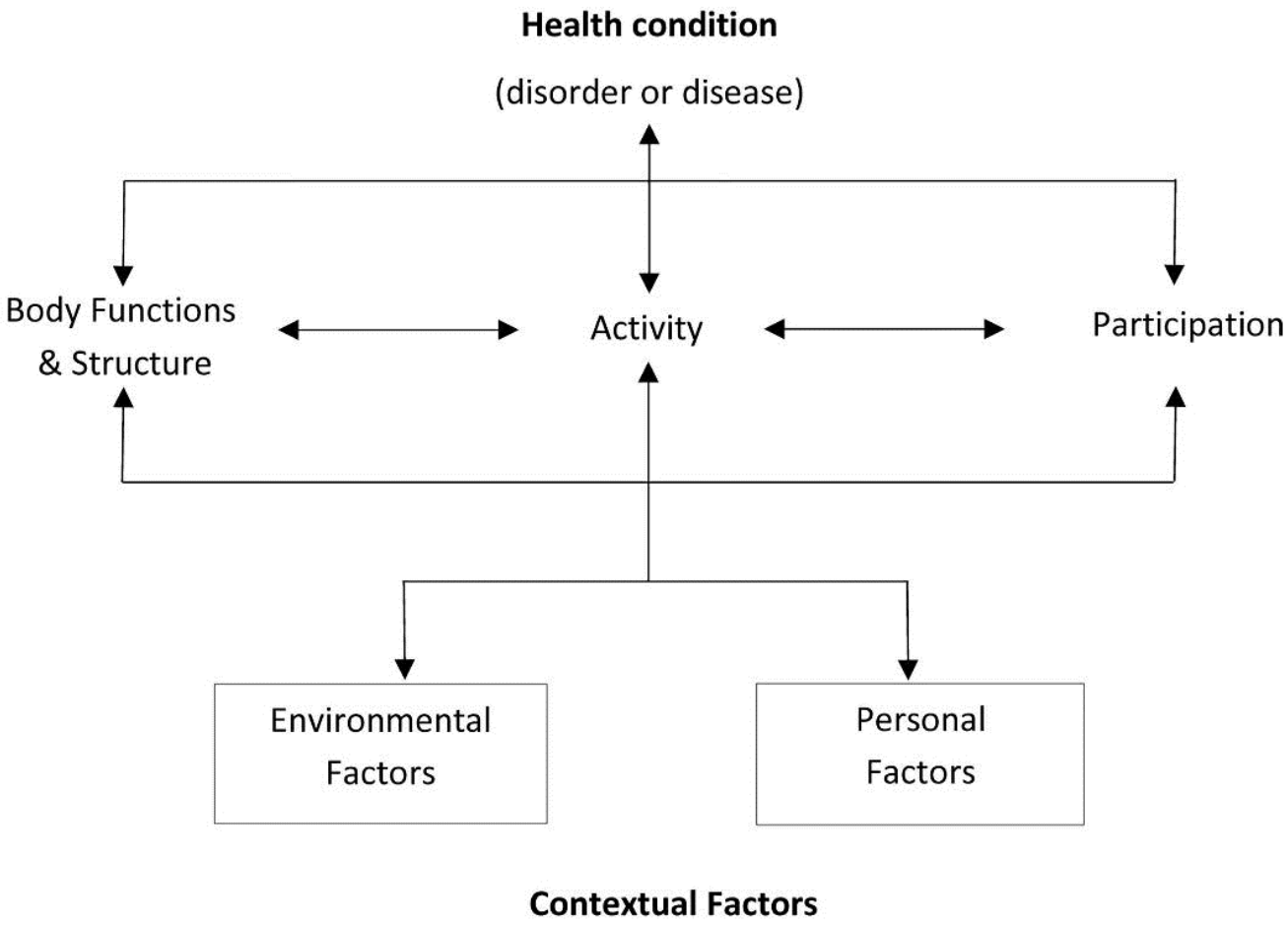

Fig 1. The ICF.

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Efforts to assess disability status in this way includes work by several international organisations. The Washington Group on Disability Statistics was established as a United Nations Statistical Commission City Group in 2001, and has developed a short and extended set of questions on functioning for adults, and a functioning module for children aged 2–17 [13, 16]. The WHO have produced the WHO Disability Assessment Schedule (WHODAS) to measure and assess disability and health in relation to the ICF, and more recently, the Model Disability Survey (MDS), in collaboration with the World Bank [17, 18].

A third methodology is to objectively measure clinical impairments or the presence of specific, potentially disabling health conditions, e.g. visual acuity or seizure history. This approach focuses on objectively determining whether the individual has impairments or health conditions that affect the "body function and structure" component of the ICF. Objective screening criteria on cause and severity can aid service planning and produces reliable and comparable data [11]. However, impairment data alone do not capture how the individual functions in his or her environment (i.e. activity limitations and participation restrictions) and the overall disability experience. Additionally, impairment surveys have typically focussed on one impairment only and are comparatively expensive to conduct through reliance on clinical examiners and specialist equipment.

Comprehensive surveys of disability that assess both reported activity/functional limitations and clinical impairments or health conditions are absent from the literature. The aim of this study was to explore the interaction between measures of clinical impairment and reported functional limitation in estimating disability prevalence within the ICF, through studies in India and Cameroon.

Methods

2.1 Study Overview

We undertook a population-based disability survey in one district each of Cameroon (Fundong Health District, North-West Region, 2013) and India (Mahbubnagar District, Telengana State, 2014). We screened for disability using i) self-reported functional limitation and ii) clinical assessment of impairment (visual, hearing, musculoskeletal) and potentially disabling health conditions (epilepsy and depression).

2.2 Survey Population and Sampling

We conservatively estimated the all-age prevalence of disability (defined for this study as self-reported limitations and/or presence of moderate or greater clinical impairment, epilepsy or depression) to be 4% in both India and Cameroon [8, 19]. This required a sample of 4,056 per country, assuming precision of 20%, 95% confidence, a design effect of 1.4 and 20% non-response.

Using probability proportionate to size sampling, 51 clusters of 80 people were selected using the most recent census data (rural and urban units) in each country [20–22].Households within clusters were selected using compact segment sampling. A map of each cluster was divided into segments of approximately 80 people. One segment was randomly selected and enumerators visited each household in that segment until 80 eligible participants (permanent household members in selected households) were enumerated. Permanent household members were defined as: 1) has lived in the selected household at least six months of the last year 2) eats shared meals 3) does not pay rent to other household members.

Enumerated participants were invited to attend the survey screening at a central community location over two consecutive days. Those who were not able to attend the central location (e.g. due to mobility restriction) were examined in their homes at the end of the second day.

2.3 Screening Methodology

All participants were screened for both i) self-reported functional limitations and ii) clinical impairments/disabling health conditions.

Self-reported functional limitations were assessed using the Washington Group Extended Set on Functioning (ten core/ four non-core domains) and the draft UNICEF/Washington Group Extended Set on Child Functioning and Disability (eight core/ four non-core domains) with response options as described in Table 1 [14][23]. These modules were selected following a scoping review of the literature conducted in 2013, and considered both to be the most comprehensive and the most readily comparable to clinical measures (see below). We followed the Washington Group recommended cut-off for moderate or above difficulty (at least "a lot of" difficulty in any one domain) and restricted this to core domains only[24]. Non-core domains in the modules included pain, fatigue, anxiety and depression, and these were excluded from the case-definition given that work to refine and field-test these questions is ongoing[25]. Caregivers reported for children 2–7; children aged 8–17 in India and 8–20 in Cameroon self-reported in the presence of a caregiver, unless unable to communicate directly; and adults aged 18+ in India and 21+ in Cameroon self-reported unless a proxy was needed for communication purposes.

Clinical impairments and two potentially disabling health conditions (epilepsy and depression) were assessed using pre-existing tools. The tool, methodology and severity threshold for each are described in Table 1. Epilepsy was included given that-self reported tools do not include questions on seizure history. However, previous research has shown an association both between epilepsy and lower health-related quality of life, and between accidents during seizures and long term physical impairment[26]. To our knowledge, depression (considered one of the leading health conditions related to disability globally) is the only common mental disorder for which a clinical screen has been validated in both India and Cameroon [27, 28].

Table 1. Impairment and Health Condition Screening, Examination and Case Definition Criteria.

	Tool	Stage	Age	Method	Severity Thresholds
SRFL	UNICEF/ Washington Group Module on Child Functioning & Disability[23]	*Screen*	0–1	None[1]	-
			2–7	Caregiver report on 12 functional domains assessed on reported severity scale of limitation in completing activities related to domain	Response categories: i) No difficulty; ii) Some difficulty; iii) A lot of difficulty; iv) Cannot do
			I: 8–17 C: 8–20	As above; self report in caregiver presence	
	Washington Group Extended Set on Functioning [29]	*Screen*	I: 18 + C:21+	14 functional domains assessed on reported severity scale of limitation in completing activities related to domain; self report	
V	Adapted Rapid Assessment of Avoidable Blindness (RAAB) [30]	*Screen*	<2	Fix and Follow	Cannot fix and follow
			2–4	Finger counting	Cannot count fingers
			5+	Visual Acuity (VA) (presenting and pinhole if VA <6/18) measured via tumbling 'E' chart	Presenting vision in better eye: i)No impairment: VA $\geq$ 6/18; ii) Moderate: VA<6/18 but $\geq$6/60; iii) Severe: VA <6/60 but $\geq$3/60; iv) Profound (blind): VA<3/60
		Exam	All ages	Examination to determine cause using direct ophthalmoscope by ophthalmic nurse (Cameroon) or ophthalmic assistant (India) if meet impairment criteria	
H	WHO Ear and Hearing Disorders Examination Protocol[31]	*Screen*	0–3	Oto-Acoustic Emissions (OAE) Test	OAE Test Failure in both ears
			4+	OAE Test followed by Pure Tone Audiometry if OAE fails in both ears	Audiometry reading in better ear:
					Children (4–17): i) No impairment: <35dBA; ii) Moderate: 35-60dBA; iii) Severe: 61-80dBA; iv) Profound (deaf): >80dBA
					Adults: i) No impairment: <41dBA; ii) Moderate: 41-60dBA; iii) Severe: 61-80dBA; iv) Profound (deaf): >80dBA
		Exam	All ages	Otoscopy examination to determine cause by an ENT Nurse (Cameroon) or audiologist (India) if meet impairment criteria	
MSI	Rapid Assessment of Musculoskeletal Impairment (RAM) [32]	*Screen*	0–7	Caregiver report 6 questionss[2] followed by examination if affirmative	Physiotherapist observed effects on the ability of the musculoskeletal system to function as a whole, categorised as: i) No impairment; ii) Mild; iii) Moderate; iv) Severe
			8+	As above; self report	
		Exam	All ages	Examination by physiotherapist including standardised observation of activities	
E	(RAM) [32]	*Screen*	0–7	Caregiver report of 3 questions to assess frequency and type of seizure activity	Reported three or more generalised tonic-clonic seizures in the past 12 months
			8+	As above; self report	
D	Patient Health Questionnaire (PHQ9) [33]	*Screen*	18+	Three self-reported screening questions with a further six questions if screen is positive	Composite score: i) None: 0–4; ii) Mild: 10–14; iii) Moderately Severe: 15–19; iv) Severe: 20–27

Column 1 acronyms: SRFL–self reported functional limitation; V–visual impairment; H–hearing impairment; MSI–musculoskeletal impairment; E–Epilepsy; D–depression

[1]No tools for this age group available

[2]In India, a seventh question on chronic back pain was added

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Participants identified as having a vision, hearing or musculoskeletal impairment (henceforth MSI) were examined by the relevant clinician in the team to determine cause and refer to services as appropriate. In Cameroon, each team consisted of one Ear Nose and Throat nurse, one physiotherapist or orthopaedic clinical officer, one ophthalmic nurse and seven non-clinical fieldworkers. In India, each team comprised one audiologist, one physiotherapist, one vision technician or ophthalmic assistant and seven non-clinical fieldworkers.

Mild MSI and mild hearing impairment were recorded in both settings. In India, mild visual impairment was also recorded.

2.4 Definition of disability

A participant was classified as having a disability in this study if they:

- Screened positive to any moderate/severe clinical impairment (vision, hearing, musculoskeletal) or severe potentially disabling health condition (epilepsy or depression)–"clinical" cases.
- Reported significant functional limitations ("a lot of difficulty" or "cannot do") in any core functional domains. Children aged 2–17 years: seeing, hearing, walking, self-care, understanding, being understood, learning, remembering; Adults 18+ years: seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care, upper body strength, fine motor dexterity.)–"self-reported" cases.

All participants who were classified as having a disability ("cases") were further interviewed about socio-demographics, poverty, livelihoods, education, health, water and sanitation, activities and participation.

Participation scores were generated using a question set developed by SINTEF which assesses ability to perform a range of activities in the respondents' current environment[34]. Domains include: self-care, domestic life, interpersonal behaviours, major life areas (school/work) and community/civic life. Each question was scored on a response scale: "no difficulty", "moderate difficulty", "severe difficulty" and "inability to perform".

2.5 Training and translation

In India, all tools were translated into Telegu and back-translated by an independent translator. Any differences between the translated and original version were discussed and the translations were modified accordingly. The primary language in the Cameroon site was English, however the population in the study area also spoke both Pidgin English and Nkom. Interviewers were recruited who spoke all three languages, and the quality of their verbal translation into these languages was assessed: the interviewers asked the question in the local language and an independent person translated this back into English. Differences were noted and discussed, and a phonetic phrase-sheet of standard translations of terms (e.g. depression, anxiety, assets) was developed to ensure consistency. Cognitive testing of the questionnaires was then carried out in each site to assess feasibility and understanding.

Three teams per country were trained for ten days on disability sensitivity and project protocols. This included formal inter-observer variation testing of all clinical screens, and an observed practice of the full protocol on thirty volunteers.

2.6 Data Entry and Analysis

Data were analysed using STATA 12.0. The 'svy' command was used to derive prevalence estimates accounting for cluster sampling. Predictors of the agreement between the different disability measures were analysed using logistic regression. Specifically, we assessed demographic

(age, sex) and impairment-related (severity, type) predictors of people with clinical impairments also reporting functional limitations. Mean participation scores among participants screening positive for the different disability measures were compared using the student t-test. Cross-tabulations were conducted to describe the relationship between i) any level reported functional limitation in seeing and any level visual impairment ii) any level reported limitation in hearing and any level hearing impairment iii) any level reported limitation in walking, climbing, upper body strength and fine motor skills and any level muscular-skeletal impairment, iv) any level of reported limitation and any level clinical impairment aggregated across the domains above.

2.7 Ethical Considerations

Ethical Approval was granted by:

- The London School of Hygiene & Tropical Medicine (UK)
- National Ethics Committee for Research in Human Health (CNERSH, Cameroon)
- Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon)
- Indian Institute of Public Health Hyderabad Institutional Ethics Committee (India)
- Government of India Health Ministry Screening Committee (India)

Medicines for minor health ailments were distributed by clinical team members where appropriate and participants with unmet health needs were referred to relevant services. Written (signature or thumb print) informed consent was obtained from all participants. Caregivers provided consent for participants <18 years in India and <21 years in Cameroon in accordance with country ethics.

Results

The survey response rate was 87% in Cameroon (n = 3567) and 88% in India (n = 3574) (Table 2). There were more females than males in the Cameroon sample (59%), in agreement with the 2005 Census (52% female)[20]. In India, 52% of the sample were female compared with 50% in the 2011 Census [21]. Consequently, the results are self-weighted.

Table 2. Sample age and sex characteristics in Cameroon and India.

	Cameroon						India					
	Males		Females		Total		Males		Females		Total	
Age group (years)	n	%	n	%	n	%	n	%	n	%	n	%
0–9	609	42	630	30	1,239	35	365	21	345	18	710	19
10–19	399	27	423	20	822	23	353	2.1	320	17	673	19
20–29	77	5	307	15	384	11	277	16	356	19	633	18
30–39	70	5	197	9	267	7	214	13	284	15	498	14
40–49	67	5	152	7	219	6	185	11	207	11	392	11
50–59	61	4	146	7	207	6	143	8	173	9	316	9
60–69	60	4	127	6	187	5	116	7	118	6	234	7
70–79	66	5	86	4	152	4	42	2	46	2	88	2
80+	46	3	44	2	90	3	13	1	17	1	30	1
Total	**1455**	**41**	**2122**	**59**	**3,567**	**100**	**1708**	**48**	**1866**	**52**	**3574**	**100**

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3.1 Overall Prevalence of Disability

The overall population prevalence of disability (defined as reporting significant functional limitations and / or having a moderate or severe clinical impairment, epilepsy or depression) was 10.5% (95% CI 9.0–12.2) in Cameroon and 12.2% (10.6–14.1) in India (Table 3). In both countries, the prevalence was similar in women and men and increased exponentially with age.

3.2 Prevalence of Significant Functional Limitations

Significant functional limitation was reported by 5.9% of participants in Cameroon and 7.5% in India ("self-reported" cases) (Table 4). In both countries, the most commonly reported functional limitations among children (aged 2–17) were in walking, remembering and learning. Amongst adults (18+), difficulties in walking/climbing, seeing and hearing were most commonly reported.

3.3 Prevalence of clinical impairments and specific health conditions

Overall, 8.4% (95% CI 7.5–9.4) in Cameroon and 10.5% (9.4–11.7) in India screened positive for one or more impairment/health condition ("clinical" cases) (Table 4). Prevalence increased rapidly with age (data not shown). In both countries the most prevalent impairment across all ages was hearing impairment (Cameroon: 3.6% India: 4.4%), followed by MSI (Cameroon: 3.4% India: 3.5%), and visual impairment (Cameroon: 2.3% India: 3.5%).

3.4 Relationship between disability measurement approaches

Fig 2 describes the relationship between self-reported and clinical cases amongst the participants identified to have a disability.

One third (33%) of participants in Cameroon who were identified as having a disability, and 45% in India, were both self-reported cases and clinical cases (Category B).

A smaller proportion (Category A, 21% in Cameroon, and 14% in India) were self-reported cases, but not clinical cases. This category included people who (not mutually exclusive):

- Screened positive for mild clinical impairments below the severity threshold defined as "clinical cases" (Cameroon: 41% of category, India: 74% of category).
- Reported significant functional limitations in domains not directly screened clinically (e.g. remembering, concentrating) (Cameroon: 68%, India: 84%)
- Reported functional limitations in domains which when evaluated clinically were found not to be impaired (e.g. hearing and walking) (Cameroon: 24%, India 41%)

Almost half of participants who were identified as having a disability in each setting (Cameroon: 47%, India: 41%), were clinical cases but not self-reported cases (Category C). The vast

Table 3. Overall Disability Prevalence in Cameroon and India.

		Cameroon		India	
		n	% (95% CI)	n	% (95% CI)
Overall Prevalence of Disability		373	10.5 (9.0–12.2)	437	12.2 (10.6–14.1)
Sex	Male	144	9.9 (8.3–11.7)	199	11.7 (9.7–14.0)
	Female	229	10.8 (9.0–13.0)	238	12.8 (10.9–14.8)
Age Group	0–17	91	4.7 (3.7–5.9)	44	3.6 (2.6–4.9)
	18–49	68	6.9 (5.3–9.1)	137	8.1 (6.0–11.0)
	50+	214	33.6 (28.8–38.9)	256	38.3 (33.6–43.3)

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majority of people in this group reported at least "some" functional limitations in at least one domain, but no core domains in which they had "a lot of difficulty" or were "unable" to complete the activity (case definition for "self-reported case"). Amongst those in Category C this

Table 4. Reported Functional Limitations and Clinical Impairments in Cameroon and India[1].

		Cameroon		India	
		n	% (95% CI)	n	% (95% CI)
Reported Functional Limitations					
Any Reported Functional Limitation		197	5.9 (4.7–7.4)	258	7.5 (5.9–9.4)
Children 2–17	Any reported functional limitation	44	2.6 (1.8–3.6)	25	2.3 (1.4–3.7)
	Seeing	6	0.4 (0.1–0.9)	3	0.3 (0.1–1.2)
	Hearing	6	0.4 (0.2–0.8)	5	0.5 (0.2–1.1)
	Walking	13	0.8 (0.4–1.5)	9	0.8 (0.4–1.6)
	Understanding	6	0.4 (0.2–0.8)	10	0.9 (0.5–1.7)
	Being Understood	7	0.4 (0.2–0.9)	8	0.7 (0.3–1.5)
	Learning	11	0.6 (0.3–1.2)	10	0.9 (0.4–1.9)
	Remembering	15	1.1 (0.6–2.0)	7	0.8 (0.4–1.6)
	Self-Care	4	0.3 (0.1–0.8)	6	0.7 (0.3–1.5)
Adults 18+	Any Reported functional limitation	153	9.5 (7.4–12.1)	233	9.9 (7.9–12.4)
	Seeing	48	3.0 (2.0–4.3)	85	3.6 (2.4–5.4)
	Hearing	33	2.0 (1.3–3.2)	86	3.7 (2.8–4.7)
	Walking/climbing	89	5.5 (4.1–7.3)	112	4.8 (3.6–6.2)
	Communicating	7	0.4 (0.2–1.0)	21	0.9 (0.6–1.4)
	Remembering/ Concentrating	46	2.9 (1.9–4.2)	31	1.3 (0.7–2.4)
	Self-Care	19	1.2 (0.7–1.9)	34	1.4 (1.0–2.0)
	Upper Body Strength	19	1.2 (0.7–1.9)	46	2.0 (1.5–2.6)
	Fine Motor Skills	14	0.9 (0.5–1.5)	32	1.4 (0.8–2.2)
Clinical Impairments					
Any clinical impairment/ disabling health condition		294	8.4 (7.5–9.4)	376	10.5 (9.4–11.7)
Vision Impairment	All Vision impairment*	82	2.3 (1.8–3.0)	124	3.5 (2.7–4.4)
	Moderate	55	1.9 (1.3–2.6)	91	2.8 (2.2–3.7)
	Severe	10	0.3 (0.2–0.6)	16	0.5 (0.3–0.9)
	Profound (blind)	17	0.6 (0.3–1.0)	14	0.4 (0.2–0.9)
Hearing Impairment	All Hearing impairment*	127	3.6 (2.8–4.6)	157	4.4 (3.7–5.2)
	Moderate	76	2.5 (1.9–3.2)	102	3.1 (2.4–3.8)
	Severe	15	0.5 (0.3–0.8)	34	1.0 (0.7–1.5)
	Profound (deaf)	9	0.3 (0.1–0.6)	15	0.5 (0.2–0.9)
Musculoskeletal Impairment	All MSI*	123	3.4 (2.7–4.4)	125	3.5 (2.9–4.3)
	Moderate	113	3.2 (2.5–4.0)	80	2.2 (1.8–2.8)
	Severe	10	0.3 (0.2–0.5)	44	1.2 (0.8–1.8)
Health Conditions and Multiple Impairments	Epilepsy	25	0.7 (0.5–1.0)	63	1.8 (1.4–2.2)
	Clinical Depression (>17 only)	7	0.4 (0.2–0.9)	26	1.1 (0.7–1.6)
	Multiple Impairments	59	1.7 (1.2–2.1)	91	2.5 (2.1–3.1)

[1]Table describes proportion of sample reporting "a lot of difficulty" or "cannot do" to any basic domain

* "All" impairment refers to all moderate or greater impairment. Severity estimates for vision and hearing are restricted to >4 and >3 years respectively as severity was not determined below these age groups for each screen

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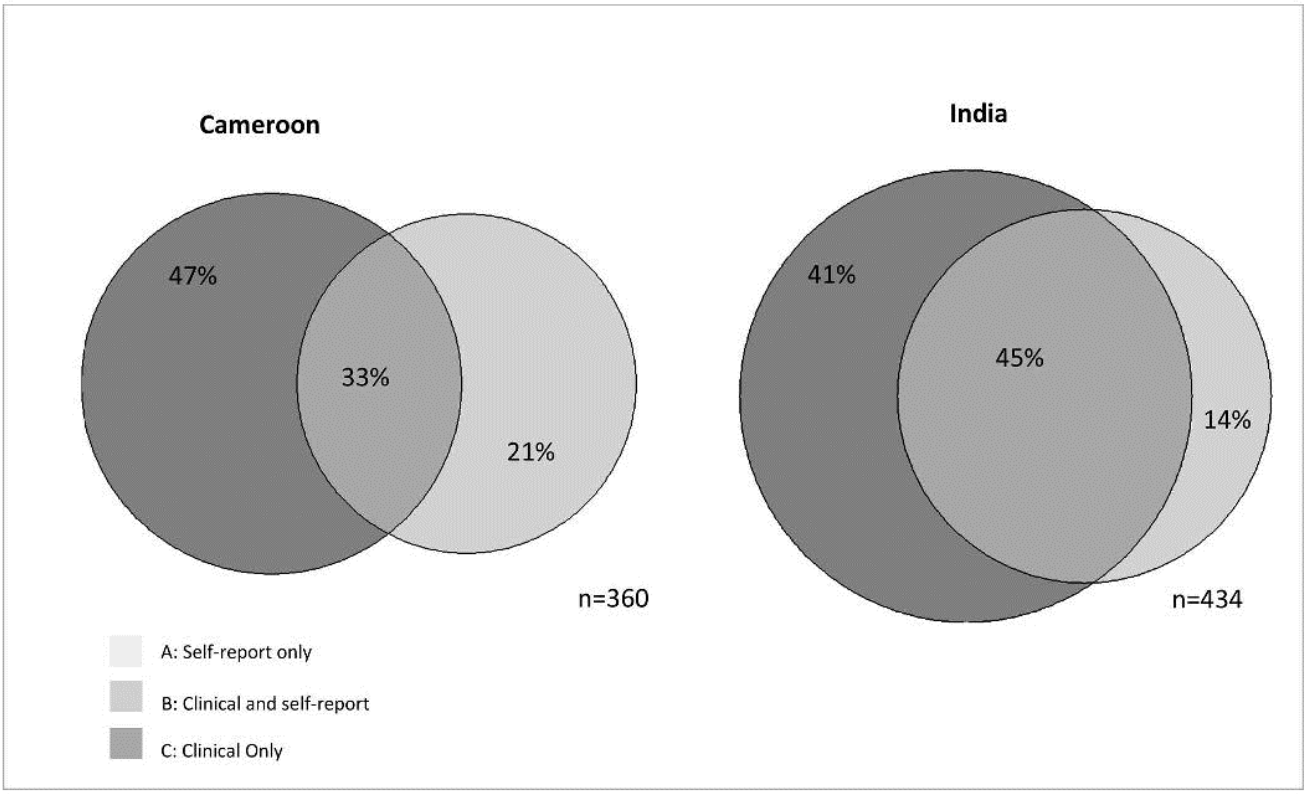

Fig 2. Relationship between disability measures in Cameroon and India.

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included: 93% of adults in both countries, 69% of children in Cameroon and 53% of children in India.

Expanding the case-definition for reported functional limitations to include either i)"some difficulty" in any basic domain, or ii)"some difficulty in any two domains" substantially increases the all-age prevalence of disability via self-report in Cameroon to 58.3% (95% CI 55.2–61.3) and 35.3% (32.7–38.1) respectively. In India, the prevalence of disability increased to 47.0% (44.0–50.1) and 27.6% (24.9–30.5) respectively. Expanding the case-definition to "some difficulty" in any basic domain would redefine 77.2% of Category C (clinical only) in Cameroon and 79.3% in India as Category B (clinical and self report) but would diminish Category B as a proportion to 12.7% (11.1–14.6) in Cameroon and and 20.4% (18.3–22.7) in India due to the large increase in Category A (self-report only).

Table 5 gives aggregate cross tabulations between clinical impairment severity in vision, hearing and MSI and the corresponding domains of the Washington Group (children 2–17: seeing, hearing, walking; adults: seeing, hearing, walking, upper body strength and fine motor skills). In both settings less than ten percent of participants reporting "no difficulties" were identified to have any level of impairment in the same domain. Approximately half of participants in India and one third in Cameroon who reported "some" difficulty in one of the domains directly measured clinically were determined to have a mild or above impairment. In addition, analysis for each of the three domains separately showed that this proportion ranged between less than twenty percent for sensory domains in both settings, and 22% (Cameroon) and 48% (India) in the physical domain in Cameroon and India respectively (data not shown).

Table 5. Cross tabulation of clinical severity versus reported limitation[1].

		Most severe clinical impairment[2]				
		None	**Mild**	**Moderate**	**Severe/Profound**	**Total[3]**
	India					
Most significant functional limitation	None	1769 (90%)	162 (8%)	16 (1%)	10 (1%)	1957 (100%)
	Some	499 (49%)	410 (40%)	82 (8%)	34 (3%)	1025 (100%)
	A lot/ Can't do	12 (5%)	43 (18%)	89 (38%)	92 (39%)	236 (100%)
	Total	2280 (71%)	615 (19%)	187 (6%)	136 (4%)	3218 (100%)
	Cameroon					
	None	1555 (95%)	52 (3%)	33 (2%)	3 (1%)	1643 (100%)
	Some	790 (68%)	247 (21%)	106 (9%)	16 (1%)	1159 (100%)
	A lot/ Cant do	28 (18%)	26 (17%)	64 (42%)	35 (23%)	153 (100%)
	Total	2373 (80%)	325 (11%)	203 (7%)	54 (2%)	2955 (100%)

[1]Combined cross-tabulation between i) any difficulty seeing, hearing, walking, upper body strength and motor skills and ii) any level visual, hearing or physical impairment. Restricted to age 5 and above based on severity data

[2]If multiple clinical impairments, most severe used in analysis.

[3]Cameroon missing hearing severity data for 23 participants excluded from analysis

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In India, a single question "Do you consider yourself [your child] to have a disability" was included. Only 3.8% (95% CI 2.9–4.9) of the overall sample answered affirmatively. This included 25.5% of clinical cases, and 42.3% of self-reported cases (data not shown). Amongst those who answered "yes" to the single question, 14.1% were neither a self-reported nor clinical case.

3.5 Predictors of being a self-reported case amongst clinical cases

Table 6 explores predictors amongst clinical cases of also being a self-reported case (Categories B and C).

In India amongst clinical cases, adults aged ≥ 66years were more likely than adults aged 34–49 years to also be a self-reported case (OR 2.9, 95% CI 1.5–5.7). There was no association with age in Cameroon or sex in either setting. Clinical cases were more likely to also be self-reported cases if their impairments were severe (Cameroon: OR = 4.0, 95% CI 1.7–9.4, India: 2.5, 1.5–4.1) or profound (Cameroon: 6.2, 2.4–16.3, India: 3.5, 1.4–8.8) compared to moderate. Having multiple (Cameroon: 6.6, 2.7–15.9, India: 4.0, 2.0–7.7) or physical (Cameroon: 3.1, 1.4–7.0, India: 4.8, 2.2–10.4) impairments compared to vision impairment was also significantly associated with also being a self-reported case in both settings.

3.6 Participation restrictions among people with disabilities

Table 7 shows the maximum and mean participation scores for i) self-reported cases only (Category A), ii) self-reported and clinical cases (Category B) and iii) clinical cases only (Category C). Higher scores indicate greater participation restriction. We compared participation scores in i) Category A with Category B and ii) Category B with Category C, for adults (≥17 years) and children (5–16 years) separately. Among adults in both countries, participation restriction scores were significantly higher for Category B (self-report and clinical cases) compared to Category A (self-report cases only) and Category C (clinical cases only). In Cameroon, restrictions were slightly higher ($p<0.01$) amongst Category C compared to Category A, but there was no difference between these categories in India. There was no difference in participation restriction by any case category amongst children in either country.

Table 6. Odds of reporting a functional limitation amongst participants screening positive for clinical impairments in Cameroon and India.

	Cameroon					India				
	Clinical and self-report (n = 118)		Clinical only (n = 168)		Adjusted OR (95% CI)	Clinical and self-report (n = 197)		Clinical only (n = 176)		Adjusted OR (95% CI)
	n	%	n	%		n	%	n	%	
Age (years)										
2–17	20	17	39	23	0.9 (0.3–2.7)	17	9	17	10	1.3 (0.6–2.9)
18–33	12	10	17	10	1.3 (0.4–4.4)	19	9	21	12	1.0 (0.5–2.3)
34–49	7	6	13	8	**baseline**	31	16	37	21	**baseline**
50–65	19	16	27	16	1.4 (0.5–4.0)	72	37	76	43	1.1 (0.6–2.0)
66+	60	51	72	43	1.5 (0.6–4.1)	60	31	25	14	2.9 (1.5–5.7)
Sex										
Male	50	42	61	36	**baseline**	83	42	90	51	**baseline**
Female	68	58	107	64	0.8 (0.5–1.2)	114	58	86	49	1.4 (0.9–2.2)
Severity of impairment[1]										
Moderate	73	65	136	90	**baseline**	95	49	108	73	**baseline**
Severe	19	17	9	6	4.0 (1.7–9.4)	76	39	33	22	2.5 (1.5–4.1)
Profound	20	18	6	6	6.2 (2.4–16.3)	22	11	7	5	3.5 (1.4–8.8)
Type of impairment[2]										
Vision	12	10	35	21	**baseline**	28	14	48	28	**Baseline**
Musculoskeletal	39	33	39	23	3.1 (1.4–7.0)	41	21	16	9	4.8 (2.2–10.4)
Hearing	26	22	58	35	1.4 (0.6–3.1)	52	27	43	25	2.1 (1.1–4.0)
Epilepsy	1	1	16	10	0.2 (0.1–1.7)	4	2	38	22	0.2 (0.5–0.6)
Multiple	39	33	19	11	6.6 (2.7–15.9)	69	36	27	16	4.0 (2.0–7.7)

[1]Cameroon: missing severity data for 23 participants excluded; India: missing severity data for 29 participants excluded

[2]Depression excluded from analysis due to low number (n = 2 Cameroon, n = 7 India)

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Discussion

4.1 Summary of results

The overall disability prevalence estimated in the study was 10.5% (95% CI 9.0–12.2) in Cameroon and 12.2% (10.6–14.1) in India, reflecting all participants who either self-reported significant functional limitation (5.9% [4.7–7.4] in Cameroon and 7.5% [5.9–9.4] in India) or screened positive clinically to a moderate or severe impairment or disabling health condition

Table 7. Participation restrictions amongst people with disabilities in Cameroon and India.

		Cameroon						India					
		Cat A: self-report only Case		Cat B: Clinical and self-report Case		Cat C: Clinical only Case		Cat A: self-report only Case		Cat B: Clinical and self-report Case		Cat C: Clinical only Case	
Age group	Max score possible[1]	Mean Score	SD	Mean Score	SD	Mean Score	SD	Mean Score	SD	Mean Score	SD	Mean Score	SD
Children (5–16)	60	22.1	5.7	23.3	9.5	18.3	5.2	40.0	18.2	28.6	12.2	20.7	9.9
Adults (17+)	84	26.7*	13.6	38.1	13.6	31.2*	9.1	36.1*	15.3	45.9	16.2	34.3*	11.9

*P<0.01 from independent t-test comparing i) Category A vs B and ii) Category B vs C

[1]NB Higher scores denote greater participation restrictions

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(8.4% [7.5–9.4] in Cameroon and 10.5% [9.4–11.7] in India). As expected, disability prevalence in both countries increased exponentially with age, irrespective of how disability was measured. Use of a single question on disability in India identified less than one third (26.5%) of those otherwise classed as having a disability.

These figures are higher than other country prevalence estimates of disability. In Cameroon, the 2011 Demographic and Health Survey estimated an all-age prevalence of 5.4%, whilst a 2010 study by Cockburn et al. in North-West Cameroon estimated a regional prevalence of 6.2%[35, 36]. However, both studies used measures of self-reported functional limitation only, showing similarity with the self-report estimates in the present study. In India, the 2011 country census estimated a country-wide prevalence of 2.2%, using a single disability screening question with multiple "type of disability" response categories. This is consistent with our finding that use of a single question on disability in India identified fewer than one third of those otherwise defined as having a disability. Moreover, the similarity of findings across both countries reflects a consistency and standardisation of the methods used.

Very few previous studies have considered the agreement between measures of self-reported functional limitations and clinical screening. One study by Kempen et al. (1996) found discrepancies between self-reported and performance-based motor and sensory limitations amongst the elderly, related to socio-demographic factors and personality traits [37]. Our study showed a considerable lack of overlap between the people identified as having a disability via reported functional limitation and via clinical screening. Many who reported significant limitations only (Category A) either had mild clinical impairments or reported limitations not directly screened clinically. Amongst those who screened positive clinically only (Category C), the vast majority had reported "some" difficulty in at least one functioning domain, but no domains with "a lot of difficulty" or "cannot do" (the case definition for self-reported limitations. However, incorporating "some difficulty" into the threshold for significant functional limitation further widened the discrepancy between measures through large inflation of Category A, increasing the overall prevalence of disability to approximately half the population. Further, our data showed that considering those self-reported domains which were directly screened clinically (vision, hearing and physical) 40% of participants who reported "some" difficulty in seeing, hearing or walking/upper body strength/fine motor skills in India, and 21% in Cameroon screened positive for mild impairments, whilst half in India and two thirds in Cameroon were not identified to have any level of impairment in the corresponding impairment categories.

In adults, participation restrictions were highest amongst those who both screened positive for clinical impairments and reported significant functional limitations (Category B), although there was no relationship by case category in children.

4.2 Implications of findings

The disparity between the sub-populations identified using a reported functional limitation tool and a battery of impairment screens has several major implications.

Firstly, this result provides evidence that clinical impairment tools in isolation do not adequately capture all significant functional limitations, with 21% of those with disability in Cameroon and 14% of those in India not identified via clinical tools.

Secondly, that 46% of those considered to have a disability in Cameroon and 41% in India, were identified via objective clinical measures but did not report a significant functional limitation and would therefore be missed by surveys using reported functioning tools only. Specifically, participants with moderate impairments or impairments in vision or hearing, were less likely to self-report functional limitations. From the perspective of universal health coverage and delivery of health and rehabilitative interventions, this may be inadequate. Several studies

have highlighted the "hierarchy" of disability [38, 39]. Namely, that impairments considered less critical to the individual's participation, may not be reported. This is shown in the current study in that participants with physical impairments in both study settings (both predominantly agricultural) were far more likely to report a significant limitation in functioning in the corresponding domain (walking and climbing) than participants with vision or hearing impairments. Moreover, this suggests that not all participants with impairments affecting their functioning or participation report these limitations/restrictions. If this is the case, surveys using self-reported tools only may underestimate disability.

Thirdly, our study adds to the considerable ongoing debate related to appropriate measures for population-based disability measurement within the ICF, and the theoretical basis for determining the population of interest [40, 41]. It is imperative to acknowledge that disability is an umbrella concept and that measurement at the level of impairments, activity limitations or participation restrictions, and the triangulation of these tools, will identify different samples. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as "an evolving concept that [..] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"[42]. Considering this as our population of interest, our findings suggest that using a self-reported tool in isolation is perhaps too restrictive at the level of "a lot" and too broad at the level of "some" to determine this sub-population, but that a self-reported tool with additional clinical screens for all who report "some" difficulty will identify the vast majority of people who experience either a moderate or greater clinical impairment, or participation restriction.

One solution, where resources allow, might therefore be to screen populations first with the Washington Group Questions to measure the magnitude of significant functional limitations ("a lot of difficulty" or "cannot do") and provide a comparable estimate of disability between countries and over time. Secondly, a simple clinical screen could be administered to all participants who respond to having at least "some" difficulty in a specific domain so that all moderate/severe impairments are identified and the appropriate referrals to maximise functioning offered. This approach would identify 94% of people with disabilities in Cameroon and 95% in India, based on the present study criteria, although further work is needed to address screening for mental health disorders and cognitive impairments. The use of mid-level clinicians as opposed to specialists in this study increases the feasibility of this approach. In addition, recent innovations in mobile tools for impairment screening would decrease the burden on clinical team members, who would only need to visit participants failing the screen criteria to provide any diagnosis or referral as appropriate [43, 44]. Finally, this data could be triangulated with a tool to measure participation restrictions and external barriers in order to provide more contextual information about the lives of people with disabilities. Further development of such tools and this methodology is needed.

We acknowledge that the lack of clinical screens for common mental disorders (other than depression), and for cognitive impairment, makes a comprehensive exploration of tools to measure disability difficult to achieve. This is a critical limitation in the field of disability measurement, particularly in a survey setting, and is considered a priority by leading scholars in global mental health [25, 45–47].

It is also important to acknowledge that different methodologies impact on comparability of disability prevalence estimates and available information, even within the broader classification of self-reported functioning tools. Multiple international agencies, including several United Nations agencies, have agreed to endorse the "short-set" Washington Group Questions for upcoming data collection. However, work is ongoing to further develop and finalise other tools, including the Washington Group Extended Set used in this study and the Model

Disability Survey (developed after our study was conducted) [48]. Future research should consider similar triangulation of these tools with both clinical tools and tools to evaluate participation restriction, so as to assess comprehensive compatibility with the ICF.

4.3 Study Strengths and limitations

The study used a robust sampling methodology to provide estimates of disability compatible with the ICF. The study measured and compared the relationship between different components of disability, adding to the evidence base in this important measurement area.

However, tools and diagnostic tests for assessing mental health and cognitive impairments in this study were limited. The findings of the present study will be used to inform the Washington Group Working Group on Mental Health and further this goal.

Finally, PTA and OAE testing was affected particularly in Cameroon by environmental conditions and consistently high background noise, increasing the risk of false positives.

Conclusion

Tools to assess reported functional limitation alone are insufficient to identify all persons with moderate or severe clinical impairments that impact on participation. A self- reported tool followed by clinical screening of all those who report "some difficulty" in functioning would identify 94% of people with disabilities in Cameroon and 95% in India, based on the study criteria. This would allow data to be collected using the internationally agreed and comparable standard (self-report) whilst also ensuring adequate information on impairments and participation restrictions for service provision. However, further work is needed on field tools for assessment of common mental disorders and cognitive impairment to comprehensively assess disability within the ICF.

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Chapter Seven: Additional Prevalence Data

7.1 Introduction

Chapter Six presented the overall disability prevalence, combining moderate or worse clinical impairments, epilepsy, severe depression and significant reported functional limitations. This section presents the additional prevalence estimates for domain specific self-reported functional limitations and impairments in Cameroon and India. The prevalence estimates are disaggregated by age group, gender and severity of limitation or impairment. For clarity, estimates included in the overall disability prevalence estimates are shaded blue.

7.2 Functional Limitations and the single question

7.2.1 Children age 2-17

Tables 19 and 20 describe the prevalence of all functional limitations included in the UNICEF/ Washington Group Extended Set for Functioning for children 2-17. Prevalence is reported at the level of at least 'some difficulty' and at least 'a lot of difficulty' The comparative single question 'do you consider yourself/your child to have a disability' was included in India, and is also reported for participants in this setting (Table 21 only).

Amongst all children 2-17, the most common functional limitations at the level of at least 'some difficulty' were learning (Cameroon: 20.8%, 95% CI 18.2 – 23.8; India: 11.4, 9.3 – 13.8) and controlling behaviour (C: 23.2%, 20.4 – 26.2; I: 10.7, 8.1 – 14.0). Amongst those aged five and above only, the most commonly reported limitations were in remembering (C: 28.8, 25.3 – 32.6; I: 10.7, 8.1 – 14.0), accepting change (C: 22.6, 19.4 – 26.2; I: 5.6, 3.9 – 8.0) and, in Cameroon, completion of a task (18.8, 16.0 – 21.9). There were no differences by gender in any domain.

At the level of at least 'a lot of difficulty/ cannot do', the most commonly reported domains across all children 2-17 in Cameroon were controlling behaviour (3.2, 2.3 – 4.5) and walking (0.8, 0.4 – 1.5). Amongst those 5-17, common domains included worry (3.4, 2.3 – 5.1) and accepting change (2.0, 1.3 – 3.0). In India, the most

commonly reported domains across all children 2-17 were playing (1.1, 0.6 – 2.1) and controlling behaviour (1.0, 0.5 – 2.0). Amongst those 5-17 only, the most common limitations were in accepting change (1.0, 0.5 – 2.1) and getting along with other children (1.0, 0.5 – 2.2). There were no differences by gender across all domains.

Using the single question in India, 2.2% (1.5 – 3.3) of children age 2-17 were reported to have a disability, comprising 2.8% (1.7 – 4.6) of boys and 1.5% (0.8 – 3.0) of girls.

Table 19: Cameroon Reported Functional Limitations Prevalence by age and gender: children													
		Total				Male				Female			
		Some*		A lot /cannot do		Some*		A lot /cannot do		Some*		A lot /cannot do	
		n	%	n	%	n	%	n	%	n	%	n	%
2 -17	Seeing	99	5.8 (4.5 – 7.4)	6	0.4 (0.1 – 0.9)	47	5.5 (4.1 – 7.5)	3	0.4 (0.1 – 1.1)	52	6.0 (4.2 – 8.5)	3	0.3 (0.1 - 1.1)
	Hearing	130	7.6 (6.4 – 8.9)	6	0.4 (0.2 – 0.8)	62	7.3 (5.8 – 9.2)	2	0.2 (0.1 – 0.9)	68	7.9 (6.2 – 10.0)	4	0.5 (0.2 – 1.2)
	Walking	93	5.4 (4.0 – 7.2)	13	0.8 (0.4 – 1.5)	53	6.2 (4.5 – 8.6)	9	1.1 (0.5 – 2.3)	40	4.6 (3.2 – 6.7)	4	0.5 (0.1 – 1.5)
	Understanding	86	5.0 (3.7 – 6.7)	6	0.4 (0.2 – 0.8)	40	4.7 (3.1 – 7.0)	2	0.2 (0.1 – 1.0)	46	5.3 (3.8 – 7.3)	4	0.5 (0.2 – 1.2)
	Being Understood	83	4.8 (3.8 – 6.2)	7	0.4 (0.2 – 0.9)	32	3.8 (2.6 – 5.5)	4	0.5 (0.1 – 1.6)	51	5.9 (4.4 – 7.9)	3	0.3 (0.1 – 1.1)
	Learning	357	20.8 (18.2 – 23.8)	11	0.6 (0.3 – 1.2)	177	20.8 (17.3 – 24.9)	6	0.7 (0.3 – 1.5)	180	20.8 (17.6 – 24.5)	5	0.6 (0.2 – 1.6)
5+	Remembering	388	28.8 (25.3 – 32.6)	15	1.1 (0.6 – 2.0)	203	29.7 (25.3 – 34.6)	8	1.2 (0.5 – 2.5)	185	27.9 (23.8 – 32.3)	7	1.1 (0.5 – 2.1)
	Self-care	79	5.9 (4.5 – 7.5)	4	0.3 (0.1 – 0.8)	44	6.4 (4.7 – 8.8)	3	0.4 (0.1 – 1.4)	35	5.3 (3.7 – 7.5)	1	0.2 (0.1 – 1.1)
2 -17	Controlling Behaviour	397	23.2 (20.4 – 26.2)	55	3.2 (2.3 – 4.5)	200	23.6 (20.1 – 27.4)	23	2.7 (1.7 – 4.3)	197	22.8 (19.3 – 26.8)	32	3.7 (2.4 – 5.7)
	Playing	69	4.0 (3.0 –5.3)	11	0.6 (0.3 – 1.2)	33	3.9 (2.8 – 5.4)	6	0.7 (0.3 – 1.5)	36	4.2 (2.8 – 6.2)	5	0.6 (0.2 – 1.6)
5+	Worry	270	20.0 (16.5 – 24.1)	46	3.4 (2.3 – 5.1)	139	20.4 (16.4 – 24.9)	26	3.8 (2.4 – 6.0)	131	19.7 (15.7 – 24.5)	20	3.0 (1.8 – 4.9)
	Completion of Task	253	18.8 (16.0 – 21.9)	22	1.6 (1.0 – 2.7)	137	20.1 (16.5 – 24.2)	11	1.6 (0.9 – 2.9)	116	17.5 (14.5 – 20.8)	11	1.7 (0.9 – 3.0)
	Accept Change	305	22.6 (19.4 – 26.2)	27	2.0 (1.3 – 3.0)	158	23.1 (19.5 – 27.2)	16	2.3 (1.4 – 3.9)	147	22.1 (17.9 – 27.0)	11	1.7 (0.9 – 3.2)
	Get along with other children	59	4.4 (3.2 – 6.1)	5	0.4 (0.2 – 0.9)	32	4.7 (2.9 – 7.4)	3	0.4 (0.1 – 1.4)	27	4.1 (2.7 – 6.1)	2	0.3 (0.1 – 1.2)

*Refers to *at least* some difficulty

= included in overall disability prevalence estimate (Chapter Six)

Table 20: India Reported Functional Limitations Prevalence by age and gender: children													
		Total				Male				Female			
		Some*		A lot /cannot do		Some*		A lot /cannot do		Some*		A lot /cannot do	
		n	%	n	%	n	%	n	%	n	%	n	%
2 -17	Seeing	46	4.2 (2.7 – 6.3)	3	0.3 (0.1 – 1.2)	23	4.0 (2.5 – 6.3)	1	0.2 (0.1 – 1.3)	23	4.4 (2.5 – 7.6)	2	0.4 (0.1 – 1.5)
	Hearing	38	3.5 (2.5 – 4.7)	5	0.5 (0.2 – 1.1)	20	3.5 (2.2 – 5.4)	2	0.3 (0.1- 1.4)	18	3.4 (2.1 – 5.5)	3	0.6 (0.2 – 1.8)
	Walking	39	3.5 (2.5 – 5.0)	9	0.8 (0.4 – 1.6)	17	3.0 (1.7 – 5.1)	6	1.0 (0.4 – 2.5)	22	4.2 (2.7 – 6.4)	3	0.6 (0.2 – 1.8)
	Understanding	84	7.6 (5.6 – 10.4)	10	0.9 (0.5 – 1.7)	47	8.2 (5.8 – 11.5)	5	0.9 (0.3 – 2.4)	37	7.0 (4.6 – 10.6)	5	1.0 (0.4 – 2.2)
	Being Understood	77	7.0 (5.0 – 9.6)	8	0.7 (0.3 – 1.5)	42	7.3 (4.8 – 10.9)	4	0.7 (0.2 – 2.2)	35	6.7 (4.6 – 9.6)	4	0.8 (0.3 – 2.0)
	Learning	125	11.4 (9.3 – 13.8)	10	0.9 (0.4 – 1.9)	70	12.2 (9.5 – 15.5)	5	0.9 (0.3 – 2.4)	55	10.5 (7.7 – 14.0)	5	1.0 (0.3 – 2.6)
5+	Remembering	151	17.4 (14.1 – 21.2)	7	0.8 (0.4 – 1.6)	78	16.9 (12.9 – 21.8)	4	0.9 (0.3 – 2.2)	73	18.0 (14.1 – 22.	3	0.7 (0.2 – 2.3)
	Self-care	33	3.8 (2.5 – 5.8)	6	0.7 (0.3 – 1.5)	16	3.5 (2.2 – 5.5)	3	0.6 (0.2 – 2.0)	17	4.2 (2.3 – 7.6)	3	0.7 (0.2 – 2.3)
2 -17	Controlling Behaviour	118	10.7 (8.1 – 14.0)	11	1.0 (0.5 – 2.0)	56	9.7 (7.4 – 12.8)	4	0.7 (0.3 – 1.8)	62	11.8 (8.2 – 16.6)	7	1.3 (0.6 – 3.0)
	Playing	54	4.9 (3.3 – 7.3)	12	1.1 (0.6 – 2.1)	25	4.3 (2.7 – 6.9)	7	1.2 (0.5 – 3.0)	29	5.5 (3.5 – 8.6)	5	1.0 (0.3 – 2.6)
5+	Worry	59	6.8 (4.7 – 9.7)	7	0.8 (0.4 – 1.8)	22	4.8 (3.0 – 7.5)	4	0.9 (0.3 – 2.9)	37	9.1 (6.0 – 13.6)	3	0.7 (0.2 – 2.2)
	Completion of Task	71	8.2 (6.2 – 10.7)	8	1.0 (0.5 – 1.8)	41	8.9 (6.4 – 12.2)	3	0.6 (0.2 – 2.0)	30	7.4 (5.0 – 10.8)	5	0.1 (0.5 – 2.9)
	Accept Change	49	5.6 (3.9 – 8.0)	9	1.0 (0.5 – 2.1)	28	6.1 (4.1 – 8.9)	4	0.9 (0.3 – 2.3)	21	5.2 (3.2 – 8.2)	5	1.2 (0.5 – 2.9)
	Get along with other children	39	4.5 (2.8 – 7.0)	9	1.0 (0.5 – 2.2)	18	3.9 (2.3 – 6.5)	4	0.9 (0.3 -2.8)	21	5.2 (3.0 – 8.8)	5	1.2 (0.5 – 2.9)
Single Question Yes		27	2.2 (1.5 – 3.3)	-	-	18	2.8 (1.7 – 4.6)	-	-	9	1.5 (0.8 – 3.0)	-	-

*Refers to *at least* some difficulty

= included in overall disability prevalence estimate (Chapter Six)

7.2.2 Adults age 18 and above

Tables 21, 22 and 23 report the prevalence amongst adults age 18+ in all domains included in the Washington Group Extended Set on Functioning, by severity, age group and gender. Domains related to worry and depression are scored based on a combined indicator created across responses to one question on frequency ('daily', 'weekly', 'monthly', 'a few times a year'), and one on intensity ('a little', 'a lot', 'somewhere between a little and a lot'), for each domain respectively. Appendix 5 provides the syntax for creation of the combined indicator, and the mapping of this indicator onto the categories 'some' and 'a lot/cannot do'. Tables 22 and 23 also include the comparative single question 'do you consider yourself to have a disability', which was included in India.

At the level of at least 'some difficulty', the most commonly reported functional limitations in Cameroon amongst all adults 18+ were in walking (46.4, 42.5 – 50.3), seeing (38.0, 35.0 – 41.1) and remembering/concentrating (37.4, 34.3 – 40.5). In India, these were fatigue (39.2, 35.4 – 43.0), pain (37.8, 33.7 – 42.1) and seeing (34.3, 31.4 – 37.2). In Cameroon, functional limitations were significantly higher amongst those 50+ compared to those aged 18-49, in all domains except communicating, remembering/concentrating, worry and depression. In India, functional limitations were significantly higher in the older age group in all domains except pain and fatigue. There were no differences by gender in any domain in either setting.

At the level of at least 'a lot of difficulty', the most commonly reported limitations amongst all adults 18+ in both settings were pain (C: 19.1, 16.9 – 21.6; I:13.8, 11.2 – 16.7), fatigue (C: 8.3, 7.1 – 9.7 I: 5.8, 4.5 – 7.6), walking/climbing (C: 5.5, 4.1 – 7.3; I: 4.8, 3.6 – 6.2) and seeing (C: 3.0, 2.0 – 4.3; I: 3.6, 2.4 – 5.4). Reported limitations were significantly higher amongst adults 50+ compared to adults 18-49 in Cameroon in all domains except communicating and depression, and India in all domains except worry, depression and pain. Reported depression was higher in women than men on India, but there were no other differences by gender in any domain in either setting.

Using the single question for comparison in India, 4.6% (3.5 – 6.0) of adults aged 18 and above responded affirmatively. This increased with age group to 9.1% (7.0 – 11.8) of adults aged 50+ but did not differ by gender.

Table 21: Cameroon Reported Functional Limitations Prevalence by age: adults												
	Total				18-49				50+			
	Some*		A lot /cannot do		Some*		A lot /cannot do		Some*		A lot /cannot do	
	n	%	n	%	n	%	n	%	n	%	n	%
Seeing	613	38.0 (35.0 – 41.1)	48	3.0 (2.0 – 4.3)	216	22.1 (19.3 – 25.2)	4	0.4 (0.2 – 1.1)	397	62.4 (57.6 – 67.0)	44	6.9 (4.8 – 9.9)
Hearing	314	19.5 (17.4 – 21.7)	33	2.0 (1.3 – 3.2)	106	10.8 (8.7 – 13.5)	6	0.6 (0.3 – 1.3)	208	32.7 (28.7 – 37.0)	27	4.2 (2.5 – 7.2)
Walking or climbing	748	46.4 (42.5 – 50.3)	89	5.5 (4.1 – 7.3)	303	31.0 (27.4 – 34.8)	18	1.8 (1.2 – 2.9)	445	70.0 (65.6 – 74.0)	71	11.2 (8.3 – 14.9)
Communicating	67	4.2 (3.1 – 5.5)	7	0.4 (0.2 – 1.0)	39	4.0 (3.0 – 5.3)	5	0.5 (0.2 – 1.2)	28	4.4 (2.7 – 7.0)	2	0.3 (0.1 -1.3)
Remembering or Concentrating	603	37.4 (34.3 – 40.5)	46	2.9 (1.9 – 4.2)	319	32.7 (29.4 – 36.1)	13	1.3 (0.7 – 2.5)	284	33.7 (30.1 – 49.3)	33	5.2 (3.4 – 7.8)
Self-care	123	7.6 (5.6 – 10.3)	19	1.2 (0.7 – 1.9)	38	3.9 (2.4 – 6.3)	3	0.3 (0.1 – 1.0)	85	13.4 (9.9 – 17.8)	16	2.5 (1.4 – 4.3)
Upper Body Strength	147	9.1 (7.6 – 10.9)	19	1.2 (0.7 – 1.9)	47	4.8 (3.4 – 6.8)	3	0.3 (0.1 – 1.0)	100	15.7 (13.0 – 18.9)	16	2.5 (1.5 – 4.3)
Fine Motor Skills	232	14.4 (11.5 – 17.8)	14	0.9 (0.5 – 1.5)	90	9.2 (6.7 – 12.5)	2	0.2 (0.1 – 0.8)	142	22.3 (18.1 – 27.2)	12	1.9 (1.0 – 3.4)
Worry	462	28.6 (25.9 – 31.6)	41	2.5 (1.9 – 3.4)	280	28.7 (24.9 – 32.8)	22	2.3 (1.5 – 3.4)	182	28.6 (25.0 – 32.6)	19	3.0 (1.9 – 4.7)
Depression	348	21.6 (19.0 – 24.4)	28	1.7 (1.1 – 2.6)	210	21.5 (18.4 – 24.9)	12	1.2 (0.6 – 2.5)	138	21.7 (18.2 – 25.6)	16	2.5 (1.5 – 4.1)
Pain	380	23.6 (21.0 – 26.3)	308	19.1 (16.9 – 21.6)	147	15.0 (12.5 – 18.0)	113	11.6 (9.5 – 14.0)	233	36.6 (32.8 – 40.7)	195	30.7 (26.8 – 34.8)
Fatigue	233	14.4 (12.7 – 16.4)	134	8.3 (7.1 – 9.7)	108	11.1 (9.0 – 13.5)	57	5.8 (4.5 – 7.5)	125	19.7 (16.3 – 23.5)	77	12.1 (9.8 – 14.9)

*Refers to *at least* some difficulty

= included in overall disability prevalence estimate (Chapter Six)

Table 22: India Reported Functional Limitations Prevalence by age: adults												
	Total				18-49				50+			
	Some*		A lot /cannot do		Some*		A lot /cannot do		Some*		A lot /cannot do	
	n	%	n	%	n	%	n	%	n	%	n	%
Seeing	805	34.3 (31.4 – 37.2)	85	3.6 (2.4 – 5.4)	368	21.9 (19.0 – 25.1)	26	1.5 (0.7 – 3.6)	437	65.5 (61.2 – 69.6)	59	8.8 (6.5 – 12.0)
Hearing	396	16.9 (15.0 – 18.8)	86	3.7 (2.8 – 4.7)	160	9.5 (8.0 – 11.3)	25	1.5 (0.9 – 2.5)	236	35.4 (31.3 – 39.7)	61	9.1 (6.6 – 12.5)
Walking or climbing	692	29.5 (26.5 – 32.6)	112	4.8 (3.6 – 6.2)	309	18.4 (15.3 – 21.8)	24	1.4 (0.6 – 3.1)	383	57.4 (52.0 – 62.7)	88	13.2 (10.6 – 16.3)
Communicating	180	7.7 (6.0 – 9.8)	21	0.9 (0.6 – 1.4)	81	4.8 (3.4 – 6.9)	10	0.6 (0.3 – 1.2)	99	14.8 (11.6 – 18.8)	11	1.6 (0.9 – 3.0)
Remembering or Concentrating	572	24.4 (21.4 – 27.5)	31	1.3 (0.7 – 2.4)	318	18.9 (16.0 – 22.2)	20	1.2 (0.5 – 2.7)	254	38.1 (33.1 – 43.3)	11	1.6 (0.8 – 3.3)
Self-care	224	9.5 (8.0 – 11.3)	34	1.4 (1.0 – 2.0)	65	4.9 (2.8 – 5.4)	4	0.2 (0.1 – 0.6)	159	23.8 (19.9 – 28.3)	30	4.5 (3.0 – 6.7)
Upper Body Strength	256	10.9 (9.0 – 13.1)	46	2.0 (1.5 – 2.6)	76	4.5 (3.1 – 6.4)	7	0.4 (0.2 – 0.9)	180	27.0 (22.6 – 31.9)	39	0.6 (4.3 – 8.0)
Fine Motor Skills	204	8.7 (6.9 – 10.8)	32	1.4 (0.8 – 2.2)	63	3.7 (2.5 – 5.6)	10	0.6 (0.2 – 2.0)	141	21.1 (16.8 – 26.3)	22	3.3 (2.2 – 4.9)
Worry	554	23.6 (20.6 – 26.9)	84	3.6 (2.6 – 4.8)	350	20.8 (17.7 – 24.3)	46	2.7 (1.9 – 3.9)	204	30.6 (26.0 – 35.6)	38	5.7 (3.6 – 8.8)
Depression	436	18.6 (15.8 – 21.7)	83	3.5 (2.5 – 4.9)	275	16.3 (13.6 – 19.5)	47	2.8 (1.9 – 4.1)	161	24.1 (19.9 – 28.9)	36	5.4 (3.5 – 8.3)
Pain	888	37.8 (33.7 – 42.1)	324	13.8 (11.3 – 16.7)	621	36.9 (32.8 – 41.3)	202	12.0 (9.7 – 14.8)	267	40.0 (34.6 – 45.7)	122	18.3 (13.9 – 23.6)
Fatigue	920	39.2 (35.4 – 43.0)	137	5.8 (4.5 – 7.6)	629	37.4 (33.6 – 41.3)	76	4.5 (2.2 – 6.2)	291	43.6 (38.2 – 49.3)	61	9.1 (6.7 – 12.3)
Single Question Yes	108	4.6 (3.5 – 6.0)	-	-	47	2.8 (1.8 – 4.4)	-	-	61	9.1 (7.0 – 11.8)	-	-

*Refers to *at least* some difficulty

= included in overall disability prevalence estimate (Chapter Six)

Table 23: Reported Functional Limitations Prevalence by gender: adults								
Cameroon								
	Male				**Female**			
	Some*		**A lot /cannot do**		**Some***		**A lot /cannot do**	
	n	%	n	%	n	%	n	%
Seeing	200	41.2 (35.7 – 46.9)	20	4.1 (2.4 – 6.9)	413	36.6 (33.4 – 40.1)	28	2.5 (1.6 – 3.8)
Hearing	92	18.9 (15.3 – 23.2)	11	2.4 (1.3 – 4.0)	222	19.7 (17.5 – 22.0)	22	2.0 (1.2 – 3.3)
Walking or climbing	215	44.2 (38.3 – 50.3)	33	6.8 (4.7 – 9.8)	533	47.3 (43.4 – 51.2)	56	5.0 (3.5 – 6.9)
Communicating	17	3.5 (1.9 – 6.4)	2	0.4 (0.1 – 1.7)	50	4.4 (3.2 – 6.0)	5	0.4 (0.2 – 1.2)
Remembering or Concentrating	145	29.8 (25.8 – 34.2)	17	3.5 (2.2 – 5.5)	458	40.6 (37.2 – 44.1)	29	2.6 (1.6 – 4.1)
Self-care	38	7.8 (5.1 – 11.9)	10	2.1 (1.1 – 4.0)	85	7.5 (5.5 – 10.3)	9	0.8 (0.4 – 1.5)
Upper Body Strength	36	7.4 (5.0 – 10.8)	7	1.4 (0.7 – 3.0)	111	9.8 (8.0 – 12.0)	12	1.1 (0.5 – 2.1)
Fine Motor Skills	50	10.3 (9.1 – 14.7)	4	0.8 (0.3 – 2.2)	182	16.1 (12.9 – 20.0)	10	0.9 (0.5 – 1.7)
Worry	147	30.2 (26.1 – 34.8)	11	2.3 (1.2 – 4.1)	315	28.0 (24.5 – 31.7)	30	2.7 (1.9 – 3.7)
Depression	106	21.8 (18.4 – 25.7)	8	1.6 (0.8 – 3.4)	242	21.5 (18.5 – 24.8)	20	1.8 (1.1 – 2.9)
Pain	119	24.5 (20.3 – 29.2)	96	19.8 (16.3 – 23.7)	261	23.2 (20.4 – 26.2)	212	18.8 (16.3 – 21.7)
Fatigue	74	15.2 (12.5 – 18.4)	36	7.4 (5.3 – 10.3)	159	14.1 (12.1 – 16.3)	98	8.7 (7.3 – 10.4)
India								
Seeing	331	30.8 (27.7 – 34.2)	23	2.1 (1.0 – 4.3)	474	37.1 (33.7 – 40.7)	62	4.9 (3.4 – 6.9)
Hearing	181	16.9 (13.9 – 20.3)	35	3.3 (2.2 – 4.8)	215	16.8 (15.1 – 18.8)	51	4.0 (3.0 – 5.3)
Walking or climbing	283	26.4 (23.2 – 29.8)	46	4.3 (2.7 – 6.7)	409	32.1 (28.5 – 35.8)	66	5.2 (3.9 – 6.8)
Communicating	77	7.2 (5.3 – 9.7)	8	0.7 (0.4 – 1.4)	103	8.1 (6.1 – 10.5)	13	1.0 (0.6 – 1.8)

Remembering or Concentrating	252	23.5 (20.0 – 27.4)	10	0.9 (0.4 – 2.1)	320	25.1 (21.7 – 28.7)	21	1.6 (0.9 – 3.1)
Self-care	90	8.4 (6.6 – 10.6)	13	1.2 (0.7 – 2.1)	134	10.5 (8.6 – 12.8)	21	1.6 (1.1 – 2.5)
Upper Body Strength	103	9.6 (7.4 – 12.4)	17	1.6 (1.0 – 2.6)	153	12.0 (9.9 – 14.5)	29	2.3 (1.6 – 3.2)
Fine Motor Skills	81	7.5 (5.6 – 10.2)	16	1.5 (0.7 – 3.0)	123	9.6 (7.6 – 12.1)	16	1.3 (0.8 – 2.0)
Worry	219	20.4 (16.8 – 24.5)	26	2.4 (1.7 – 3.5)	335	26.3 (23.1 – 29.6)	58	4.5 (3.2 – 6.4)
Depression	178	16.6 (13.3 – 20.5)	23	2.1 (1.5 – 3.1)	258	20.2 (17.1 – 23.7)	60	4.7 (3.3 – 6.7)
Pain	368	34.3 (30.3 – 38.6)	137	12.8 (10.1 – 16.0)	520	40.8 (35.9 – 45.8)	187	14.7 (12.0 – 17.8)
Fatigue	390	36.3 (32.3 – 40.6)	55	5.1 (3.7 – 7.0)	530	41.5 (37.0 – 46.2)	82	6.4 (4.6 – 8.8)
Single Question Yes	53	4.9 (3.3 – 7.3)	-	-	55	4.3 (3.3 – 5.6)	-	-

*Refers to *at least* some difficulty

= included in overall disability prevalence estimate (Chapter Six)

7.3 Impairments

7.3.1 Musculoskeletal Impairment

Table 24 presents the prevalence of musculoskeletal impairment (MSI) in Cameroon and India, disaggregated by severity, age group and gender. The overall prevalence of any severity of MSI was 11.6% in Cameroon (95% CI 10.1 – 13.3) and 19.6% (16.7 – 22.8) in India. Prevalence decreased in both settings with severity, from 8.2% (6.8 – 9.8) prevalence of mild MSI in Cameroon and 16.1% (13.3 – 19.2) in India, to 0.3% (0.2 – 0.5) and 1.3% (0.9 – 1.8) prevalence of severe MSI respectively. Overall MSI prevalence and prevalence of each severity of MSI generally increased with age group in both settings, up to 41.2% (36.1 – 46.4) and 51.9% (44.7 – 59.1) prevalence of any level of MSI in those age 50+ in Cameroon and India respectively. There were no differences by gender at any severity level.

7.3.2 Visual Impairment

In Cameroon, the following WHO visual impairment categories were assessed: moderate VI, severe VI, blind. In India, early visual impairment was measured in addition.

The overall prevalence of visual impairment (moderate or worse) was 2.3% (1.8 – 3.0) in Cameroon and 8.9% (early or worse, 7.6 -10.4) in India (Table 25). Moderate impairment was more prevalent than severe or profound visual impairment across all age groups and by gender in both settings. There were few differences in prevalence between children 0-17 and adults 18-49 in either setting and no differences in gender, but prevalence overall (C: 10.9, 8.3 – 14.3; I: 34.5, 30.3 – 39.1) and by severity was considerably higher in adults aged 50+ compared to other age groups.

7.3.3 Hearing Impairment

As shown in Table 27, all-age hearing impairment prevalence was similar in Cameroon and India at 8.1% (6.7 – 9.8) and 8.8% (7.4 – 10.4) respectively,

decreasing with severity to 0.3% (0.1 – 0.6) and 0.5% (0.2 – 0.9) for profound hearing impairment in both settings. Prevalence was highest in the oldest age group in both Cameroon and India (C: 35.7, 29.9 – 41.9; I: 33.2, 28.6 – 38.2) and there were no significant differences by gender.

Table 24: Musculoskeletal Impairment Prevalence by severity, age and gender												
Cameroon												
	Total		**0-17 years**		**18-49 years**		**50+ years**		**Male**		**Female**	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any MSI	415	11.6 (10.1 – 13.3)	58	3.0 (2.1 – 4.2)	95	9.7 (7.5 – 12.4)	262	41.2 (36.1 – 46.4)	142	9.8 (8.0 – 11.8)	273	12.9 (11.2 – 14.9)
Mild	292	8.2 (6.8 – 9.8)	32	1.6 (1.1 – 2.5)	67	6.8 (5.1 – 9.2)	193	30.3 (25.3 – 35.9)	100	6.9 (5.2 – 9.0)	192	9.1 (7.6 – 10.9)
Moderate	113	3.2 (2.5-4.0)	24	1.2 (0.7 – 2.1)	24	2.4 (1.6 – 3.8)	65	10.2 (7.8 – 13.3)	39	2.7 (1.9 – 3.8)	74	3.5 (2.7 – 4.6)
Severe	10	0.3 (0.2-0.5)	2	0.1 (0.03 – 0.4)	4	0.4 (0.2 – 1.1)	4	0.6 (0.2 – 1.7)	3	0.2 (0.07 – 0.6)	7	0.3 (0.2 – 0.7)
India												
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any MSI	699	19.6 (16.7 – 22.8)	36	2.9 (2.0 – 4.4)	316	18.8 (15.0 – 23.3)	347	51.9 (44.7 – 59.1)	292	17.1 (14.2 – 20.4)	407	21.8 (18.5 – 25.5)
Mild	574	16.1 (13.3 – 19.2)	18	1.5 (0.8 – 2.6)	292	17.4 (13.8 – 21.7)	264	39.5 (32.8 – 46.7)	229	13.4 (10.7 – 16.6)	345	18.5 (15.3 – 22.2)
Moderate	80	2.2 (1.8 – 2.8)	11	0.9 (0.5 – 1.6)	16	1.0 (0.6 – 1.5)	53	7.9 (5.8 – 10.7)	41	2.4 (1.8 – 3.2)	39	2.1 (1.5 – 2.9)
Severe	45	1.3 (0.9 – 1.8)	7	0.6 (0.3 – 1.2)	8	0.5 (0.2 – 1.0)	30	4.5 (2.9 – 6.9)	22	1.3 (0.8 – 2.1)	22	1.2 (0.7 – 1.9)

= included in overall disability prevalence estimate (Chapter Six)

Table 25: Vision Impairment Prevalence by severity, age and gender[1]												
Cameroon												
	Total		**0-17 years[2]**		**18-49 years**		**50+ years**		**Male**		**Female**	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any Visual Impairment	82	2.3 (1.8 – 3.0)	8	0.4 (0.2 – 1.0)	5	0.5 (0.2 – 1.5)	69	10.9 (8.3 – 14.3)	36	2.5 (1.7 – 3.8)	46	2.2 (1.6 – 3.0)
Moderate	55	1.9 (1.3 – 2.6)	6	0.4 (0.2 – 0.5)	3	0.3 (0.1 – 1.3)	46	7.2 (5.1 – 10.2)	23	2.0 (1.2 – 3.1)	32	1.8 (1.2 – 2.7)
Severe	10	0.3 (0.2 – 0.6)	2	0.1 (0.1 – 0.6)	0	0	8	1.3 (0.6 – 2.7)	2	0.2 (0.1 – 0.7)	8	0.4 (0.2 – 0.9)
Profound (blind)	17	0.6 (0.3 – 1.0)	0	0	3	0.2 (0.1 – 0.8)	14	2.4 (1.5 – 3.8)	11	0.9 (0.5 – 1.8)	6	0.3 (0.2 – 0.9)
India												
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any Visual Impairment	284	8.9 (7.6 – 10.4)	3	0.3 (0.1 – 1.1)	53	3.2 (2.2 – 4.5)	228	34.5 (30.5 – 39.1)	119	7.8 (6.3 – 9.6)	165	9.9 (8.5 – 11.6)
Early	163	5.1 (4.2 – 6.3)	0	0	34	2.0 (1.3 – 3.1)	129	19.5 (16.1 – 23.5)	71	4.7 (3.5 – 6.1)	92	5.5 (4.5 – 6.8)
Moderate	91	2.8 (2.2 – 3.7)	2	0.2 (0.1 – 0.9)	14	0.8 (0.5 – 1.5)	75	11.3 (8.2 – 15.2)	40	2.6 (1.7 – 3.9)	51	3.0 (2.3 – 4.1)
Severe	16	0.5 (0.3 – 0.9)	1	0.1 (0.1 – 0.9)	3	0.1 (0.1 – 0.6)	12	1.8 (0.9 – 3.4)	3	0.2 (0.1 – 0.6)	13	0.8 (0.4 – 1.4)
Profound (blind)	14	0.4 (0.2 – 0.9)	0	0	2	0.1 (0.1 – 0.5)	12	1.8 (0.9 – 3.5)	5	0.3 (0.1 – 0.9)	9	0.5 (0.3 – 1.1)

[1] Data on visual impairment were missing for 49 people in Cameroon and one person in India

[2]Estimates of prevalence severity of visual impairment are restricted to participants aged ≥5 years (as VA was not determined for children aged 0-4 years) VA data missing for one person

= included in overall disability prevalence estimate (Chapter Six)

Table 26: Hearing Impairment Prevalence by severity, age and gender[1]												
Cameroon												
	Total		**0-17 years[2]**		**18-49 years**		**50+ years**		**Male**		**Female**	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any Hearing Impairment[3]	290	8.1 (6.7 – 9.8)	22	1.1 (0.7 – 1.8)	41	4.2 (2.9 – 6.0)	227	35.7 (29.9 – 41.9)	113	7.8 (6.1 – 9.8)	177	8.4 (6.8 – 10.3)
Mild	163	5.3 (4.1 – 6.7)	0	-	30	3.1 (2.1 – 4.6)	133	20.9 (16.6 – 26.0)	69	5.6 (4.2 – 7.4)	94	5.1 (3.8 – 6.8)
Moderate	76	2.5 (1.9 – 3.2)	4	0.3 (0.1 – 0.6)	2	0.2 (0.1 – 0.8)	70	11.0 (8.3 – 14.5)	26	2.1 (1.4 – 3.0)	50	2.7 (1.9 – 3.9)
Severe	15	0.5 (0.3 – 0.8)	0	0	0	0	15	2.4 (1.4 – 4.0)	5	0.4 (0.2 – 1.0)	10	0.5 (0.3 – 1.1)
Profound (deaf)	9	0.3 (0.1 – 0.6)	3	0.2 (0.1 – 0.6)	1	0.1 (0.1 – 0.8)	5	0.8 (0.3 – 1.8)	2	0.2 (0.04 – 0.7)	7	0.4 (0.2 – 0.9)
India												
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Any Hearing Impairment	314	8.8 (7.4 - 10.4)	6	0.5 (0.2 – 1.2)	86	5.1 (3.8 – 6.9)	222	33.2 (28.6)	149	8.7 (7.2 – 10.5)	165	8.8 (7.2 – 10.8)
Mild	157	4.8 (3.8 – 6.0)	0	-	51	3.0 (2.1 – 4.3)	106	15.9 (12.6 – 19.8)	78	5.0 (3.9 – 6.3)	79	4.6 (3.3 – 6.4)
Moderate	102	3.1 (2.4 – 3.8)	2	0.1 (0.1 – 0.8)	14	0.8 (0.4 – 1.6)	86	12.9 (10.5 – 15.7)	46	2.7 (1.9 – 3.7)	56	3.0 (2.3 – 3.9)
Severe	34	1.0 (0.7 – 1.5)	0	0	11	0.7 (0.3 – 1.2)	23	3.4 (2.2 – 5.4)	14	0.8 (0.4 – 1.7)	20	1.1 (0.7 – 1.6)
Profound (deaf)	15	0.5 (0.2 – 0.9)	0	0	8	0.5 (0.2 – 1.5)	7	1.0 (0.5 – 2.4)	7	0.4 (0.1 – 1.1)	8	0.4 (0.2 – 0.9)

[1] Data on hearing impairment were missing for 2 adults in India

[2]Estimates of prevalence severity of hearing impairment are restricted to participants aged ≥4 years

[3]Cameroon Severity estimates missing for 27 hearing cases excluded from severity analysis, and

= included in overall disability prevalence estimate (Chapter Six)

Table 27: Health Conditions and Multiple Impairments Prevalence by severity, age and gender[1]												
Cameroon												
	Total		**0-17 years**		**18-49 years**		**50+ years**		**Male**		**Female**	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Epilepsy	25	0.7 (0.5 – 1.0)	12	0.6 (0.4 – 1.0)	11	1.1 (0.6 – 1.9)	2	0.3 (0.08 – 1.3)	9	0.6 (0.3 – 1.1)	16	0.8 (0.5 – 1.2)
Any Clinical Depression	308	19.1 (16.0 – 22.6)	-	-	172	17.6 (14.1 – 21.6)	136	21.4 (17.7 – 25.5)	104	21.1 (17.1 – 25.8)	205	18.2 (14.8 – 22.2)
Mild	161	10.0 (8.0 – 12.4)	-	-	98	10.0 (7.6 – 13.1)	63	9.9 (7.7 – 12.6)	57	11.7 (8.8 – 15.3)	104	9.2 (7.2 – 11.8)
Moderate	115	7.1 (5.0 – 8.6)	-	-	58	5.9 (4.7 – 7.5)	57	9.0 (7.0 – 11.5)	32	6.6 (4.4 – 9.7)	83	7.4 (5.9 – 9.2)
Moderately Severe	25	1.5 (1.0 – 2.4)	-	-	12	1.2 (0.7 – 2.0)	13	2.0 (1.2 – 3.5)	10	2.0 (1.1 – 3.9)	15	1.3 (0.8 – 2.2)
Severe	7	0.4 (0.2 – 0.9)	-	-	4	0.4 (0.2 – 1.1)	3	0.5 (0.2 – 1.5)	4	0.8 (0.3 – 2.2)	3	0.3 (0.1 – 0.8)
Multiple Impairments[1]	**59**	1.7 (1.2 – 2.1)	1	0.05 (0 – 0.2)	8	0.8 (0.3 – 1.4)	50	7.9 (5.8 – 10.0)	19	1.3 (0.7 – 1.9)	40	1.9 (1.3 – 2.5)
India												
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Epilepsy	63	1.8 (1.4 – 2.2)	13	1.1 (0.6 – 1.7)	34	2.0 (1.4 – 3.0)	16	2.4 (1.5 – 3.8)	33	1.9 (1.4 – 2.7)	30	1.6 (1.1 – 2.4)
Any Clinical Depression	439	18.7 (14.9 – 23.2)	-	-	215	12.8 (8.7 – 18.4)	224	33.6 (28.1 – 39.6)	173	16.1 (12.8 – 20.1)	266	20.9 (16.3 – 26.3)
Mild	134	5.7 (3.9 – 8.4)	-	-	89	5.3 (3.3 – 8.4)	45	6.7 (4.6 – 10.0)	44	4.1 (2.7 – 6.3)	90	7.1 (4.6 – 10.7)
Moderate	173	7.4 (5.7 – 9.4)	-	-	85	5.1 (3.4 – 7.6)	88	13.2 (10.0 – 17.3)	67	6.3 (4.7 – 8.2)	106	8.3 (6.4 – 10.8)
Moderately Severe	106	4.5 (3.4 – 6.0)	-	-	34	2.0 (1.2 – 3.3)	72	10.8 (8.0 – 14.4)	53	4.9 (3.7 – 6.7)	53	4.2 (2.9 – 5.9)
Severe	26	1.1 (0.7 – 1.6)	-	-	7	0.4 (0.2 – 1.0)	19	2.8 (1.8 – 4.6)	9	0.8 (0.4 – 1.7)	17	1.3 (0.9 – 2.1)
Multiple Impairments[1]	91	2.5 (2.1 – 3.1)	5	0.4 (0.2 – 1.0)	10	0.6 (0.3 – 1.1)	76	11.4 (9.2 – 13.9)	43	2.5 (1.9 – 3.4)	48	2.6 (2.0 – 3.4)

7.3.4 Depression, Epilepsy and Multiple Impairments

Table 27 describes the prevalence of clinical depression and epilepsy. Clinical depression estimates are available for adults only. The overall prevalence of any level of clinical depression in adults 18+ was 19.1% (16.0 – 22.6) in Cameroon and 18.7% (14.9 – 23.2) in India. Prevalence was highest for mild depression in Cameroon (10.0, 8.0 – 12.4) and moderate depression (7.4, 5.7 – 9.4) in India. There were no differences by age group in Cameroon or by gender in either setting, but in India prevalence was higher in older adults (50+) compared to adults 18-49 at all severity levels except moderate depression, and overall. The all-age prevalence of epilepsy was 0.7% (0.5 – 1.0) in Cameroon and 1.8% (1.4 – 2.2) in India, with no differences by age group or gender in either setting.

The all-age prevalence of multiple impairments of moderate or worse levels of severity was 1.7% (1.2 – 2.1) in Cameroon and 2.5% (2.1 – 3.1) in India, increasing to 7.9% (5.8 – 10.0) and 11.4% (9.2 – 13.9) for adults aged 50+ respectively. No differences were observed by gender.

Chapter Eight: The Relationship between Specific Impairments and reported functional limitations

8.1 Introduction

This chapter provides extended analysis on the relationship between specific impairments assessed clinically and corresponding self-reported domains e.g. between vision impairment and reported difficulties functioning. Analysis is restricted to participants eligible for both clinical screening and self-reported tools (i.e. age 2+), and to those for whom there is no missing data for either measure.

For each pair of clinical impairment and self-reported functional domain, crude numbers and row-wise percentages are reported for i) no impairment, ii) each severity level of impairment, and iii) any level of impairment; tabulated against i) no reported difficulty, ii) 'some' reported difficulty, iii) 'a lot' of reported difficulty and iv) 'extreme/cannot do' in the relevant self-reported domain.

Sensitivity, Specificity, Positive Predictive Value (PPV) and Negative Predictive Value (NPV) are reported with the impairment considered the 'gold standard' and the self-reported domain as the test. This does not imply that the impairment tool was considered superior, but aimed to assess agreement across the two approaches.

Agreement of self-report in comparison to clinical impairment was explored in four ways for each pair:

- Any level impairment versus 'some' or greater reported difficulty
- Any level impairment versus 'a lot' or greater reported difficulty
- Moderate or worse impairment (as used in disability prevalence estimates) versus 'some' or greater reported difficulty
- Moderate or worse impairment (as used in disability prevalence estimates) versus 'a lot' or greater reported difficulty

8.2 Visual impairment vs. reported difficulties seeing

The relationship between clinically assessed visual impairment and reported difficulties seeing is shown in Tables 28 and 29. In Cameroon, visual impairment

categories were normal, moderate, severe and profound. In India, early visual impairment was also tested.

82 participants were clinically determined to have visual impairment (moderate, severe or profound) in Cameroon. Of these, 65 reported 'some' or more difficulty seeing (sensitivity = 79%). Amongst the 3,188 participants not determined to have visual impairment, 2547 reported no difficulties seeing (specificity = 80%). Sensitivity decreased to 31% and specificity increased to 99% when comparing any level of visual impairment to reporting 'a lot' or more difficulty seeing.

Amongst 284 participants in India determined to have visual impairment (early, moderate, severe or profound), 224 reported 'some' or greater difficulty seeing (sensitivity = 79%). Of the 3,165 participants not determined to have visual impairment, 2,537 reported no difficulties (specificity = 80%). Sensitivity decreased both when comparing any level of visual impairment (18%) or moderate/severe visual impairment (39%) to reporting 'a lot' of difficulty or greater, but increased to 84% when comparing moderate/severe visual impairment to reporting 'some' or greater difficulty seeing. Specificity between moderate/severe visual impairment and reporting 'some' or greater difficulty was 78%, and increased to 99% comparing either any level visual impairment, or moderate/severe visual impairment to reporting 'a lot' of difficulty or more seeing.

Table 28: Vision Impairment vs. Reported Difficulties Seeing

Cameroon								
	Self-reported difficulties[2]							
	None		**Some**		**A lot**		**Extreme/ Cannot do**	
Clinically assessed Vision Impairment[1]	n	%	n	%	n	%	n	%
No Vision Impairment	2547	80	613	19	28	1	0	-
Moderate	15	27	28	51	12	22	0	-
Severe	1	10	7	70	2	20	0	-
Profound (blind)	1	6	5	29	6	35	5	29
Any Vision Impairment	17	21	40	49	20	24	5	6
India								
No Vision Impairment	2537	80	591	19	37	1	0	-
Early	41	25	117	72	5	3	0	-
Moderate	12	17	39	54	20	28	1	1

Severe	5	15	12	36	16	48	0	-
Profound (blind)	1	7	4	29	9	64	0	-
Any Vision Impairment	60	21	172	61	51	18	1	1
[1]Vision Impairment data missing for 49 people in Cameroon [2]WG data missing for 26 people in Cameroon and 7 in India								

Table 29: Test Sensitivity Any Clinical VI versus Washington Group Responses			
Cameroon			
		WG some or more	**WG lots or more**
		% (95% CI)	% (95% CI)
Any Vision Impairment (Moderate or Worse)	Sensitivity	79 (69 – 87)	31 (21 – 42)
	Specificity	80 (78 – 81)	99 (99 – 99)
	Positive Predictive Value	9 (7 – 12)	42 (33 – 61)
	Negative Predictive Value	99 (99 – 100)	98 (98 – 99)
India			
Any Vision Impairment	Sensitivity	79 (74 – 84)	18 (14 – 23)
	Specificity	80 (79 – 82)	99 (98 – 99)
	Positive Predictive Value	26 (23 – 29)	59 (48 – 70)
	Negative Predictive Value	98 (97 – 98)	93 (92 – 94)
Moderate or worse Vision Impairment	Sensitivity	84 (77 – 90)	39 (30 – 48)
	Specificity	78 (76 – 79)	99 (98 – 99)
	Positive Predictive Value	12 (10 – 14)	54 (43 - 65)
	Negative Predictive Value	99 (99 – 100)	98 (97 – 98)

8.3 Hearing impairment vs. reported difficulties hearing

In Cameroon, of the 263 participants with hearing impairment (mild, moderate, severe or profound), 116 reported some or greater difficulty hearing (sensitivity = 44%, Tables 30 and 31). 2,743 participants were without hearing impairment, and amongst these 2,435 reported no difficulties hearing (specificity = 90%). Sensitivity was higher when comparing moderate/worse hearing impairment to reporting 'some' or greater difficulty hearing (62%), but decreased to 10% and 21% when comparing either any hearing impairment or moderate/severe hearing impairment to 'a lot' or greater reported difficulty hearing, respectively. In contrast, specificity remained very high when comparing any level hearing impairment to reporting 'a lot' or greater difficulty hearing (100%), and comparing moderate/severe hearing impairment to either reporting 'some' (89%) or 'a lot' (100%) of difficulty hearing.

Of the 306 participants identified to have hearing impairment (mild, moderate, severe or profound) in India, 183 reported at least 'some' difficulty hearing (sensitivity = 60%). Amongst 2,743 participants not identified to have a hearing impairment, 2435 did not report any difficulties hearing (specificity = 92%). Comparatively to Cameroon, sensitivity increased to 83% when comparing moderate/worse hearing impairment to reporting 'some' or greater difficulty hearing, but decreased comparing either any level hearing impairment (26%) or moderate/worse hearing impairment (51%) to reporting 'a lot' or greater difficulty hearing. Equally, specificity remained high when comparing either any level hearing impairment (100%) or moderate/severe hearing impairment (98%) to reporting 'a lot' of difficulty hearing, but was lower comparing moderate/severe hearing impairment to reporting 'some' or greater difficulty hearing (65%).

Table 30: Hearing Impairment vs. Reported Difficulties Hearing								
Cameroon								
	Self-reported difficulties							
	None		**Some**		**A lot**		**Extreme/ Cannot do**	
Clinically assessed Hearing Impairment[1]	n	%	n	%	n	%	n	%
No Hearing Impairment	2435	89	299	11	9	1	0	-
Mild	114	70	46	28	3	2	0	-
Moderate	32	42	34	45	10	13	0	-
Severe	1	7	8	53	6	40	0	-
Profound (deaf)	0	-	3	33	6	67	0	-
Any Hearing Impairment	147	56	91	35	25	10	0	-
India								
No Hearing Impairment	2706	92	230	8	11	1	0	-
Mild	97	62	57	36	3	2	0	-
Moderate	22	22	39	39	40	40	0	-
Severe	4	12	7	21	22	67	0	-
Profound (deaf)	0	-	2	13	10	67	3	20
Any Hearing Impairment	123	40	105	34	75	24	3	1
[1]Restricted to participants with severity data (excludes <4 and OAE only)								

Table 31: Test Sensitivity Any Clinical HI versus Washington Group Responses			
Cameroon			
		WG some or more	**WG lots or more**
		% (95% CI)	% (95% CI)

Any Hearing Impairment	Sensitivity	44 (38 – 50)	10 (7 – 14)
	Specificity	90 (88 – 91)	100 (100 – 100)
	Positive Predictive Value	28 (24 – 33)	75 (58 – 87)
	Negative Predictive Value	94 (94 – 95)	92 (91 – 93)
Moderate or Worse Hearing Impairment	Sensitivity	62 (53 – 71)	21 (14 – 29)
	Specificity	89 (87 – 90)	100 (99 – 100)
	Positive Predictive Value	18 (14 – 22)	68 (51 – 83)
	Negative Predictive Value	98 (98 – 99)	97 (96 – 98)
India			
Any Hearing Impairment	Sensitivity	60 (54 – 65)	26 (21 – 31)
	Specificity	92 (91 – 93)	100 (99 – 100)
	Positive Predictive Value	43 (38 – 48)	88 (79 – 94)
	Negative Predictive Value	96 (95 – 97)	93 (92 – 94)
Moderate or Worse Hearing Impairment	Sensitivity	83 (76 – 88)	51 (42 – 59)
	Specificity	65 (59 – 72)	98 (96 – 100)
	Positive Predictive Value	62 (55 – 68)	95 (88 – 99)
	Negative Predictive Value	85 (79 – 90)	75 (69 – 80)

8.4 Musculoskeletal impairment vs. Reported difficulties walking/climbing

Tables 32 and 33 show the relationship between clinically assessed MSI and reported difficulties in walking (children 2-17) or walking/climbing (adults 18+) in Cameroon and India. This is not a direct comparison given that MSI can affect functioning in different ways that may not include difficulties walking or climbing, including limiting upper body function or structure, or related activities.

Of the 405 participants with clinically assessed MSI (mild, moderate or severe) in Cameroon, 286 reported some or more reported difficulties (sensitivity = 70%). Of the 2901 participants with no clinically assessed MSI, 2,346 reported no difficulties in walking/climbing (specificity=81%). Sensitivity decreased substantially when comparing any level of MSI or moderate/worse MSI to reporting 'a lot' or greater difficulty (18% and 41% respectively), but increased to 75% when comparing moderate or worse clinical MSI to 'some' or greater reported difficulty. Specificity decreased slightly when comparing moderate/worse MSI to 'some' or greater reported difficulty (76%), but increased when comparing either any level of MSI or moderate/worse MSI to 'a lot' or greater difficulty (99% and 98% respectively).

In India, amongst the 694 participants assessed clinically to have MSI (mild, moderate or severe), 447 reported some or more difficulties (sensitivity = 64%). Amongst the 2,741 participants not assessed clinically to have MSI, 2459 reported no difficulties (specificity = 90%). Similarly to Cameroon, sensitivity decreased markedly when comparing any level of MSI to reporting 'a lot' or greater difficulty (16%) and increased to 84% when comparing moderate/worse MSI to 'some' or more reported difficulty. Specificity remained high when comparing any level of MSI to 'a lot' or greater difficulty, (100%) and comparing moderate/worse MSI to 'some' (81%) or 'a lot' (99%) or greater reported difficulty.

Table 32: Musculoskeletal Impairment vs. Reported Walking/Climbing

Cameroon								
	Self-reported difficulties							
	None		**Some**		**A lot**		**Extreme/ Cannot do**	
Clinically assessed MSI	n	%	n	%	n	%	n	%
No MSI	2,346	81	526	18	29	1	0	-
Mild	90	32	172	60	25	9	0	-
Moderate	27	25	41	37	40	36	2	2
Severe	2	25	0	0	4	50	2	25
Any MSI[1]	119	29	213	53	69	17	4	1
India								
No MSI	2459	90	274	10	8	1	0	-
Mild	227	40	307	54	37	6	0	-
Moderate	16	20	19	24	39	49	6	8
Severe	4	9	8	19	23	53	8	19
Any MSI[1]	247	36	334	48	99	14	14	2
[1]WG Data Missing for 30 people in Cameroon and 19 in India								

Table 33: Test Sensitivity Clinical MSI versus Washington Group Responses

Cameroon			
		WG some or more	**WG lots or more**
		% (95% CI)	% (95% CI)
Any Clinical MSI	Sensitivity	70 (66 – 75)	18 (14 – 22)
	Specificity	81 (79 – 82)	99 (98 – 99)
	Positive Predictive Value	34 (31– 37)	72 (62 – 80)
	Negative Predictive Value	95 (94 – 96)	90 (90 – 91)
Moderate or worse Clinical MSI	Sensitivity	75 (67 – 83)	41 (32 – 50)
	Specificity	76 (75 – 78)	98 (98 – 99)

	Positive Predictive Value	11 (9 – 13)	47 (37 – 57)
	Negative Predictive Value	99 (98 – 99)	98 (97 – 98)
India			
Any Clinical MSI	Sensitivity	64 (61 – 68)	16 (14 – 19)
	Specificity	90 (88 – 91)	100 (99 – 100)
	Positive Predictive Value	61 (57 – 65)	93 (87 – 97)
	Negative Predictive Value	91 (90 – 92)	83 (81 – 84)
Moderate or worse Clinical MSI	Sensitivity	84 (76 – 90)	62 (53 – 70)
	Specificity	81 (80 – 82)	99 (98 – 99)
	Positive Predictive Value	14 (12 – 17)	63 (54 – 71)
	Negative Predictive Value	99 (99 – 100)	99 (98 – 99)

8.5 Clinical Depression vs. reported symptoms of depression

Tables 34 and 35 report the relationship between clinically assessed depression and reported symptoms of depression amongst adults aged 18 and above. Clinically assessed depression is shown for all levels of clinical depression (mild, moderate, moderately severe, severe) and for severe only (as included in the disability prevalence estimate). Self-reported difficulties are categorised based on the WG-ESF combined frequency/intensity depression indicator described in Appendix 5. For the purpose of analysis, Level 4 (lowest) is considered analogous to no difficulty, Level 3 to 'some' difficulty, Level 2 to 'a lot' of difficulty and Level 1 (highest) to 'extreme/cannot do'.

Amongst 294 adult participants diagnosed with any level of clinical depression (mild, moderate, moderately severe or severe) in Cameroon, 252 reported 'some' or greater difficulty with symptoms related to depression (sensitivity = 86%). Of the 1,257 participants not diagnosed with clinical depression, 533 did not report any difficulties with symptoms reported to depression (specificity = 42%). Sensitivity decreased considerably when comparing both any level of clinical depression (6%) or severe clinical depression (29%) to reported symptoms equivalent to 'a lot' of difficulty, but increased to 100% when comparing severe clinical depression to 'some' or greater reported difficulty. Specificity decreased when comparing severe clinical depression to reporting 'some' or greater difficulty with symptoms related to depression, but increased to 99% and 98% respectively comparing either any

level of clinical depression or severe clinical depression to reporting 'a lot' of difficulty.

In India, of 433 participants diagnosed with any level of clinical depression (mild, moderate, moderately severe or severe), 291 reported at least 'some' difficulty with symptoms related to depression (sensitivity = 67%). 1,892 participants were not diagnosed with clinical depression and amongst these 1043 did not report any difficulties (specificity = 55%). Sensitivity decreased substantially when comparing any level of clinical depression with reporting 'a lot' of difficulty, and when comparing severe clinical depression to reporting 'some' or greater difficulty (32%) but increased when comparing severe depression to 'a lot' of difficulty (84%). Specificity remained similar when comparing severe depression to 'a lot' or greater reported difficulty (51%) but increased to 98% when comparing any level of clinical depression to 'a lot' or greater reported difficulty, and 96% when comparing severe clinical depression to 'some' or greater reported difficulty.

Table 34: Clinical depression vs. reported depression

Cameroon								
	Self-reported difficulties[1]							
	Level 4 (lowest)		**Level 3**		**Level 2**		**Level 1 (Highest)**	
Clinically assessed Depression[2]	n	%	n	%	n	%	n	%
No Depression	533	42	486	39	223	18	15	1
Mild	23	15	73	47	53	34	5	3
Moderate	18	17	35	32	46	43	9	8
Moderately Severe	1	4	8	32	14	56	2	8
Severe	0	-	0	-	5	71	2	29
Any Depression	42	14	116	39	118	40	18	6
India								
No Depression	1043	55	522	28	287	15	40	2
Mild	63	47	33	25	26	20	11	8
Moderate	45	27	45	27	60	36	19	11
Moderately Severe	30	28	19	18	47	44	10	9
Severe	4	16	4	16	9	36	8	32
Any Depression	142	33	101	23	142	33	48	11

[1]Washington Group data missing for 22 participants in India and 66 in Cameroon
[2]PHQ-9 data missing for 4 participants in India

Table 35: Test Sensitivity Any Clinical Depression versus Washington Group Responses			
Cameroon			
		WG Level 2/3 (Medium)	**WG Level 4 (Highest)**
		% (95% CI)	% (95% CI)
Any Clinical Depression	Sensitivity	86 (81 – 90)	6 (4 – 10)
	Specificity	42 (40 – 45)	99 (98 – 99)
	Positive Predictive Value	26 (23 – 29)	55 (36 – 72)
	Negative Predictive Value	93 (90 – 95)	82 (80 – 84)
Severe Depression	Sensitivity	100 (59 – 100)	29 (4 – 71)
	Specificity	37 (35 – 40)	98 (97 – 99)
	Positive Predictive Value	0.7 (0 – 2)	6 (0 – 20)
	Negative Predictive Value	100 (99 – 100)	100 (99 – 100)
India			
Any Clinical Depression	Sensitivity	67 (63 – 72)	11 (8 – 14)
	Specificity	55 (53 – 57)	98 (97 – 99)
	Positive Predictive Value	26 (23 – 28)	55 (44 – 65)
	Negative Predictive Value	88 (86 – 90)	83 (81 – 84)
Severe Depression	Sensitivity	32 (15 – 54)	84 (64 – 96)
	Specificity	96 (96 – 97)	51 (49 – 53)
	Positive Predictive Value	9 (4 – 17)	2 (1 – 3)
	Negative Predictive Value	99 (99 – 100)	100 (99 – 100)

8.6 Summary of Findings

Specificity – i.e. the proportion of participants without clinical impairments reporting no difficulties in the corresponding domain – was high (76 – 100%) across pairs, using either broad or restricted categories of both self-report and impairment severity.

Sensitivity – i.e. those with clinical impairments reporting functional limitations in the corresponding domain – was highest when comparing moderate/worse impairment to reporting at least 'some' difficulty across each of the three pairs. This ranged from 62% and 83% for HI vs. hearing in Cameroon and India respectively, to 79% and 84% for VI and 75% and 84% for MSI vs. walking/climbing. Sensitivity decreased when comparing moderate/worse impairment to reporting at least 'a lot' of difficulty across the three pairs.

However whilst Negative Predictive Value at this threshold (the proportion of those reporting no difficulties who did not have a moderate/worse impairment) was high across pairs (85 – 100%), Positive Predictive Value (the proportion of those reporting 'some' or greater difficulty that had moderate/severe impairments in the corresponding domain) was very low (9 – 18% across all pairs with the exception of 62% for hearing in India).

Chapter Nine *Paper Three:* Assessing health and rehabilitation needs of persons with disabilities in Cameroon and India

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Student	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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?	Disability and Rehabilitation		
When was the work published?	17th December 2015		
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RESEARCH PAPER

Assessing health and rehabilitation needs of people with disabilities in Cameroon and India

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ABSTRACT

Purpose: To assess the association between disability and serious health problems, and the access and uptake of health and rehabilitation services in Cameroon and India. ***Methods***: We undertook a population-based case–control study, nested within a survey in Fundong Health District, North West Cameroon (August–October 2013) and in Mahbubnagar District, Telangana State, India (February–April 2014). Disability was defined as the presence of self-reported difficulties in functioning or clinical impairments. One control without disability was selected per case, matched by age, gender and cluster. Information was collected using structured questionnaires on: socioeconomic status, health, access to health services and rehabilitation. ***Results***: Cases with disability were significantly more likely to report a serious health problem in the last year compared to controls in both India (OR = 3.2, 95% CI 2.1–4.8) and Cameroon (OR = 1.9, 1.4–2.7). The vast majority of people sought care when seriously ill, and this did not vary between cases and controls. Awareness and use of rehabilitation services was extremely low in both Cameroon and India. ***Conclusions***: Further focus is needed to improve awareness of rehabilitation services among people with disabilities in India and Cameroon to ensure that their rights are fulfilled and to achieve the goal of Universal Health Coverage.

➤ IMPLICATIONS FOR REHABILITATION

- People with and without disabilities equally seek health care in India and Cameroon.
- However, people with disabilities experience more frequent serious health problems than people without.
- Extremely few people with disabilities were aware of rehabilitation services despite their existence in the study settings.

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Introduction

Several lines of evidence show that people with disabilities are on average at higher risk of serious health events and ill health than the general population. The World Health Survey, undertaken in 2002–2004 across 51 countries, showed that people with disabilities in low and middle income countries were significantly more likely to seek inpatient and outpatient care.[1] This finding was supported by a more recent study across 30 countries which showed that children with disabilities consistently report more serious health events than children without disabilities.[2] There are several reasons why people with disabilities may have higher health care needs. This may be due to the underlying impairment or health condition, or because of higher risk of chronic conditions and other diseases.[3] People with disabilities may also need rehabilitation services or assistive technology. Furthermore, older people are both more likely to have disabilities and to experience ill health.

People with disabilities also report a wide range of barriers that they face in accessing health care. Cost is often an important barrier. The World Health Surveys showed that while one third of people without disabilities (32–33%) were unable to afford health care, this increased to half of people with disabilities (51–53%).[1,4] This can potentially cause catastrophic health expenditure among people with disabilities that can exacerbate poverty.[5] Other commonly reported barriers include physical inaccessibility of healthcare facilities, inaccessible transport options, inaccessible information, and stigma.[6,7] These barriers potentially limit the inclusion of people with disabilities in health care, and are contrary to the UN Convention of the

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Rights of Persons with Disabilities.[8] Furthermore, it is strongly argued that we will not be able to achieve Universal Health Coverage without including people with disabilities, as they make up 15% of the world's population.[1] Consequently, improving access to health and rehabilitation services among people with disabilities is a dominant aim of the World Health Organisation (WHO)'s Global Disability Action Plan 2014–2021.[9]

Few studies have assessed quantitatively whether people with disabilities have worse access to health and rehabilitation services in low and middle income countries. The World Health Survey suggests that people with disabilities were less likely to receive health care services when needed than people without disabilities.[1] In contrast, Trani and Loeb reported no association between disability and access to health in two household surveys conducted in Afghanistan and Zambia.[10] Similarly, a multi-national study on childhood disability generally showed that children sought care when they were seriously ill, whether they had a disability or not.[2] Furthermore, studies quantifying access to and experience of rehabilitation services amongst people with disabilities in low and middle income countries are lacking.

The aim of this study was to assess the impact of disability on access to health and rehabilitation services in India and Cameroon.

Methods

Study overview

We undertook an all age population-based disability survey in Fundong Health District, North West Cameroon (August–October 2013) and in Mahbubnagar District, Telangana State, India (February–April 2014). We screened for disability using both a self-reported functioning tool and a battery of clinical impairment screening tools. We undertook a case–control study, nested within this survey, of people with and without disabilities to assess the impact of disability on access to health and rehabilitation.

Study setting

Both countries are classified as lower middle income, with a poverty headcount ratio in Cameroon of 39.9% and India of 21.9%.[11] The most recent estimates available place both countries within the WHO's "critical shortage of health personnel" category, with a country average of 1.3 and 2.1 doctors, nurses and midwives per thousand population respectively.[12]

The health worker density (the number of doctors, nurses and midwives per thousand population) estimate for the study regions was lower than the respective national estimate in Cameroon (1.05 vs 1.3/1000) and higher in India (2.1 vs 3.7/1000).[13,14]

In Cameroon, a large faith-based and charity-funded referral hospital existed within the study district, providing free and subsidised services. This hospital also provided outreach services and was linked to a community-based rehabilitation programme. However, topography in the study district was mountainous, with some study sites inaccessible without off-road private transportation and significant disparity in health centre accessibility within the district.

Similarly, in India the district in which the study was held included several government or privatly run referral hospitals, although none provided free services. A State-government-run poverty reduction programme targeted people with disabilities for organisation into Self Help Groups, but evidence on coverage of this scheme was lacking.

Survey population and sampling

A two-stage sampling procedure was used, with 51 clusters of 80 people first selected using probability proportionate to size sampling (with the most recent Census in each country used as the sampling frame). Within clusters, households were selected via modified compact segment sampling.[15] Cluster sketch maps were created by team members in collaboration with village leaders, which were used to divide the clusters into segments of approximately 80 people. One segment was selected at random for inclusion and households in this segment were visited door-to-door until 80 people (of all ages) were enumerated.

At each household, a roster was compiled to record the name, age, sex and contact details of each household member. Household members were informed about the survey and invited to attend a previously identified central location over the next two days. If an eligible person did not attend the central location the enumerators visited their household at least twice to encourage attendance. If they were unable to travel to the central location (e.g. due to mobility limitation) the survey team visited them at their household at the end of the second day.

Screening for disability

Participants were screened for self-reported limitations, clinical impairments, epilepsy and depression. Epilepsy as a health condition was included given that self-reported tools do not include questions on seizure history. However, previous research has shown an

association both between epilepsy and lower health-related quality of life, and between accidents during seizures and long term physical impairment.[16]

The screening tools and protocols are described below:

Self-reported activity limitation: Children aged 5–17 years were first screened using the draft United Nations Fund for Children (UNICEF)/Washington Group module on child functioning and disability, with permission from the tool's developers. The Washington Group on Disability Statistics is a United Nations city group mandated to improve quality and comparability of disability measures.[17] Caregivers reported for children aged 5–8 years and children 9–17 years self-reported activity limitations in a range of basic and complex activity domains. Adults aged 18+ self-reported activity limitations using the Washington Group Extended Set on Functioning for Adults.[18] In both tools, activity limitations are scored on a severity scale of: no difficulty, some difficulty, a lot of difficulty and cannot do. Children aged 9+ years and adults unable to communicate directly (due to cognitive or communication difficulties) were reported for by proxy (e.g. caregiver). Participants in the study were considered to have a disability if they/their proxy responded "a lot of difficulty" or "cannot do" to any basic activity domain. For children, basic activity domains included seeing, hearing, walking, self-care, understanding, being understood, learning, remembering; while for adults these were seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care, upper body strength and fine motor dexterity.

Vision impairment: Visual acuity was assessed using a tumbling 'E' chart with 6/18 size optotype on one side and 6/60 on the other.[19] As per the WHO protocol, VA <6/18 in the better eye was categorised as moderate impairment, VA <6/60 and >3/60 as severe and VA <3/60 as blind.[20]

Hearing impairment: The WHO Ear and Hearing Disorders Survey Protocol was used to identify hearing impairment in the study.[21] Initial screening of all participants was through an otoacoustic emissions (OAE) hearing test to assess middle ear function in both ears. Participants who failed this test in both ears or for whom an OAE reading could not be taken underwent Pure Tone Audiometry (PTA) screening to assess the level of hearing impairment. Hearing in each ear was measured at 1 KHz, 2 KHz, 4 KHz, 0.5 KHz and again at 1 KHz to ensure consistency of response, and the average reading for each ear across the four frequencies was recorded.

Hearing impairment was categorised as follows, based on the WHO threshold for adults and Global Burden of Disease threshold for children:[21,22]

- Profound: >80 dba
- Severe: 61–80 db
- Moderate: 41–60 db (adults aged >18 years), 35–60 db (children <18 years)
- Normal: <41 (adults) and <35 (children)

Physical impairment and epilepsy: The Rapid Assessment of Musculoskeletal Impairment protocol developed for a national survey in Rwanda was adapted for the study.[23] Six initial screening questions were used to assess (a)difficulty using the musculoskeletal system; (b)use of mobility aid; (c)whether the participant considered any body part to be misshapen; and (d)whether they had experienced seizures. In India, a seventh question on chronic back pain was added. Any participant answering yes to at least one question was examined by a physiotherapist or orthopaedic clinical officer. The examination included standardised observation of activities to assess functioning, a physical examination, history, diagnosis, aetiology, severity and referral information. Based on these examinations and any observed functional limitations, the participant was categorised by the physiotherapist as having either no/mild/moderate/severe physical impairment and/or epilepsy.

Clinical depression: Depression was measured in those aged 18 years and above using the Patient Health Questionnaire (PHQ-9), previously validated for use In LMIC settings.[24] The PHQ-9 consists of three screening questions and a further six questions based on responses to the screen. Total scores are calculated from responses. Any participant scoring 20 or above is determined to be experiencing clinically significant symptoms of severe depression.

The definition of disability used in this study was as follows:

- Self-reported activity limitations: reporting "a lot of difficulty" or "cannot do" in any basic activity domain
- Vision impairment: presenting vision in better eye of <6/18
- Hearing impairment: presenting hearing loss in better ear of >40 dBA (adults) or >35 dBA (children)
- Musculoskeletal impairment (MSI): structure impairment with moderate effect on the musculoskeletal system's ability to function as a whole 25–49% or greater
- Epilepsy: three or more tonic clonic seizures previously
- Depression: score of 20 or above on PHQ-9 Questionnaire (aged 18+)

Nested case–control study

All participants aged 5 and above who screened positive for disability were invited to participate in the nested

case–control study. For each case we selected one age, gender and cluster-matched control. Two additional children with disabilities and one additional adult with a disability were identified per cluster through key informants (e.g. community health workers) to ensure adequate sample size for the case–control study. These participants were selected from outside the segment selected for inclusion in the population-based survey.

Cases and controls were interviewed in detail, including modules on water and sanitation, education, livelihoods, healthcare, rehabilitation, participation and environmental barriers, using existing questionnaires as far as possible. A case-only module explored access to rehabilitation and assistive devices amongst people with disabilities. This paper focuses on the health and rehabilitation module of the case–control study.

The questionnaires used were assessed for local relevance and appropriateness through discussion with local Disabled People Organisations, other experts and through pilot testing. The questionnaires and survey tools were translated into local languages and back-translated by independent translators, who were asked to comment on the appropriateness of language used for the target population. A review was held to discuss differences in the translations and to modify them accordingly and finalise the questionnaires.

Data entry and analysis

The screening data was double entered into a purpose-built Microsoft Access Database by two trained data entry clerks. The Case–Control Questionnaire was administered using ASUS Google Nexus 7 tablets.

Data from both the Screening Questionnaire and the Case–Control Questionnaire were merged in STATA 12.0 for analysis. We constructed a socio-economic status score through principal component analysis (PCA) of household assets. This SES score was then divided into quartiles. We undertook multivariable logistic regression analyses to identify differences between cases and controls in inclusion in health and rehabilitation. Conditional logistic regression was not attempted since matching was not complete, and so analyses were adjusted by the matching variables of age and gender.

Training

Three survey teams per country received 10 days training. Each team consisted of the following participants:

- Cameroon: 1 ear, nose and throat (ENT) nurse, 1 physiotherapist or orthopaedic clinical officer, 1 ophthalmic nurse, 2 enumerators, 3 field assistants and 2 interviewers
- India: 1 audiologist, 1 physiotherapist, 1 vision tech or ophthalmic assistant, 2 enumerators, 3 field assistants and 2 interviewers. Additionally, trained ophthalmologists and an ENT surgeon validated the findings and ascertained the cause of impairment.

Ethical Approval for the study was granted by:

- The London School of Hygiene and Tropical Medicine (London, UK)
- National Ethics Committee for Research in Human Health (CNERSH, Cameroon)
- Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon)
- Indian Institute of Public Health Hyderabad Institutional Ethics Committee (India)
- Government of India Health Ministry Screening Committee (India)

All participants who attended the screening were read an information sheet about the study and given the opportunity to ask questions. If they agreed to participate, written/finger-print consent was taken. For children <18 years in India and <21 years in Cameroon a caregiver was required to provide written/finger-print consent and to remain present throughout the screening.

Basic medicines were distributed by clinical team members where appropriate and all participants with unmet health or rehabilitative needs were referred to relevant services. Each participant who screened positive for a clinical impairment was examined by a clinician to determine aetiology, diagnosis and appropriate referral.

Results

The case–control study in India included 508 cases (402 identified through the survey and 106 identified through case finding) and 337 controls (Table 1). The case–control study in Cameroon included 429 cases (331 from survey and 98 from case finding) and 274 controls. The total number of controls is lower than the number of cases in both countries due to high prevalence of disability amongst adults aged 50+, and consequent limitations on the number of households available from which to identify controls. Cases and controls were well matched on gender, particularly in India. Cases were more likely to be in the oldest age category (66+) in both India and Cameroon. People with disabilities were significantly more likely to be in the poorest quartile in India, but there was no relationship between disability and socio-economic status (SES) in Cameroon. Among the cases, 66% in India and 63% in Cameroon self-reported significant activity limitations. Physical impairment (37% in India and 42% in Cameroon) and hearing

impairment (33% and 30% respectively) were the most common impairments amongst cases. These do not constitute prevalence estimates due to case finding undertaken for the case-control survey.

Cases were significantly more likely to report a serious health problem in the last year than controls in both India (OR = 3.2, 95% CI 2.1–4.8) and Cameroon (OR = 1.9, 1.4–2.7) (Table 2). The type of serious health condition varied between cases and controls. There were no clear trends in types of serious health conditions experienced. In India, people with disabilities were also significantly more likely to report high blood pressure than controls (1.8, 1.0–3.3), and they appeared more likely to have other chronic diseases, although these results were not statistically significant. This was not assessed in Cameroon. In both India and Cameroon, the vast majority of people sought treatment if they had a serious health problem, and this did not differ between cases and controls. In both settings, treatment was predominantly sought at hospitals for cases (69% India and 60% Cameroon) and controls (59% India and 34% Cameroon) followed by private doctors for both cases (25% India and 24% Cameroon) and controls (17% India and 31% Cameroon). Reported health problems increased with age in both settings and in cases and controls, but the proportion of people seeking care remained relatively constant (data available on request). Among the cases, cost was cited as the major barrier to seeking treatment in both Cameroon (77%) and India (94%). Fewer controls reported cost as the main barrier in either Cameroon (57%) or India (25%). Access to antenatal care and vaccination of children was assessed for women of reproductive age in Cameroon. The coverage of both was very high among the controls, so that it was not possible to assess a difference with cases, although coverage was lower in that group.

Cases with disabilities were asked whether they needed and used particular assistive devices, in order to ascertain coverage (Table 3). Coverage was high for walking sticks and guides in both India (87%, 86%) and Cameroon (93%, 67%). There was a high expressed need for glasses but low coverage in both India (46%) and Cameroon (33%). Coverage of hearing aids was particularly low in both India (6%) and Cameroon (24%), despite high expressed need for the device.

In India, cases expressed a low awareness, need for and receipt of rehabilitative services (Table 4). Amongst those few who reported needing the service, however, coverage was relatively high. These findings were supported by the results from Cameroon (Table 5).

Discussion

Our study showed that people with disabilities were substantially more likely to report a serious health problem in the last year than people without disabilities, in both India and Cameroon. Most people reported seeking treatment from hospitals or private doctors when they were seriously ill, and this did not differ between people with and without disabilities. This was

Table 1. Socio-demographic characteristics of cases and controls in India and Cameroon.

	India			Cameroon		
	Cases (n =508) N (%)	Controls (n =337) N (%)	Age and sex adjusted OR (95% CI)	Cases (n =429) N (%)	Controls (n =274) N (%)	Age and sex adjusted OR (95% CI)
Age group						
5–17	67 (13%)	49 (15%)	Baseline	114 (27%)	90 (33%)	Baseline
18–33	83 (16%)	76 (23%)	0.8 (0.5–1.3)	54 (13%)	45 (16%)	1.0 (0.6–1.7)
34–49	94 (19%)	84 (25%)	0.8 (0.5–1.3)	33 (8%)	42 (15%)	0.7 (0.4–1.1)
50–65	165 (33%)	111 (33%)	1.1 (0.7–1.7)	70 (16%)	51 (19%)	1.2 (0.8–2.0)
66+	99 (20%)	17 (5%)	4.2 (2.2–8.0)	158 (37%)	46 (17%)	2.9 (1.8–4.5)
Gender						
Male	231 (46%)	163 (48%)	Baseline	179 (42%)	113 (59%)	Baseline
Female	273 (54%)	174 (52%)	1.1 (0.8–1.4)	250 (58%)	161 (41%)	1.5 (0.9–2.5)
SES*						
1st Quartile (poorest)	139 (27%)	60 (18%)	1.7 (1.1–2.6)	119 (29%)	68 (27%)	1.1 (0.7–1.8)
2nd Quartile	111 (22%)	92 (27%)	0.9 (0.6–1.3)	92 (23%)	35 (14%)	1.8 (1.1–3.0)
3rd Quartile	119 (23%)	89 (26%)	1.0 (0.7–1.5)	99 (25%)	76 (30%)	0.9 (0.6–1.4)
4th Quartile (richest)	114 (22%)	85 (25%)	Baseline	94 (23%)	76 (30%)	Baseline
Disability measure**						
Self-reported activity limitation	334 (66%)			270 (63%)		
Vision impairment	134 (27%)			92 (23%)		
Hearing impairment	165 (33%)			124 (30%)		
Physical impairment	189 (37%)			179 (42%)		
Epilepsy	70 (14%)			30 (11%)		
Depression	41 (9%)			8 (2%)		
Multiple impairments	125 (25%)			75 (11%)		

*Some missing SES data (n = 36 in India and 44 in Cameroon).
**Not mutually exclusive (i.e. sum > 100%).

Table 2. Relationship of disability with serious illness and health seeking behaviour.

	India					Cameroon				
	Cases		Controls		Age and Sex Adjusted OR (95% CI)	Cases		Controls		Age and Sex Adjusted OR (95% CI)
	N	%	*N*	%		*N*	%	*N*	%	
Serious health problem in past 12 months (total)										
No	378	(74%)	303	(90%)	Baseline	251	(59%)	204	(75%)	Baseline
Yes	130	(26%)	33	(10%)	3.2 (2.1–4.8)	178	(42%)	68	(25%)	1.9 (1.4–2.7)
Diagnosis with chronic condition										
High Blood Pressure	54	(11%)	18	(5%)	1.8 (1.0–3.3)					
Diabetes	23	(5%)	9	(3%)	1.5 (0.7–3.3)					
Arthritis	35	(7%)	14	(4%)	1.4 (0.7–2.7)					
Heart Disease	12	(2%)	4	(1%)	2.3 (0.7–7.2)					
Sought care if serious health problem										
No	16	(12%)	4	(12%)	0.9 (0.3–3.1)	30	(17%)	7	(10%)	1.8 (0.7–4.3)
Yes	114	(88%)	29	(88%)	Baseline	148	(83%)	61	(90%)	Baseline
Antenatal care/vaccines (for women aged 15–49)										
Received antenatal care										
Yes						22	(92%)	30	(100%)	Baseline
No						2	(8%)	0	(0%)	0.6 (0.2–2.1)
Child vaccinated										
Yes						21	(88%)	21	(93%)	Baseline
No						3	(12%)	3	(7%)	1.8 (0.3–11.9)

Table 3. Access to and awareness of assistive devices in India and Cameroon.

	India			Cameroon		
	Need device	Use device	Coverage	Need device	Use device	Coverage
Glasses	133	61	46%	107	35	33%
Magnifying glass	3	0	0%	13	2	15%
White cane	8	6	75%	6	2	33%
Hearing aid	100	6	6%	66	16	24%
Wheelchair	27	7	26%	29	12	41%
Crutches	7	3	43%	19	6	32%
Walking stick	91	79	87%	166	154	93%
Guide	51	44	86%	21	14	67%
Standing frame	24	14	58%	3	1	33%

Table 4. Access to and awareness of rehabilitative services in India.

	Have heard of services		Have needed services		Have received services		Receiving amongst those needing services (%)
	N	%	*N*	%	*N*	%	
Medical rehabilitation	126	26	80	16	61	12	76
Assistive device services	160	33	87	18	38	8	44
Specialist educational services	54	11	26	5	23	5	88
Vocational training	49	10	25	5	22	5	88
Counselling for person with a disability	55	11	25	5	21	4	84
Counselling for parents/family	59	12	27	6	18	4	67
Welfare services	155	32	70	14	48	10	69
General health services	240	49	111	23	74	15	67
Health information	120	25	64	13	33	7	52
Traditional or faith healers	120	24	31	6	28	6	90
Legal advice	29	6	13	3	9	2	69
Specialist health services	106	22	55	11	42	9	76

true in both India and Cameroon. For those few people who did not seek treatment, cost was reported as the major barrier, particularly among cases. Coverage was relatively high for assistive devices among people with disabilities, although this could still be increased substantially. In contrast, awareness and use of rehabilitation services was very low among people with disabilities.

Other studies in the literature have showed that people with disabilities are more at risk of serious health events and ill health than the general population.[1–3] These studies are cross sectional in nature, and therefore causality cannot be determined. However, there are a number of plausible explanations for the association between disability and heightened frequency of serious health conditions. Firstly, this may be because people

Table 5. Access to and awareness of rehabilitative services in Cameroon.

	Have heard of services		Have needed services		Have received services		Receiving amongst those needing services (%)
	n	%	*n*	%	N	%	
Medical rehabilitation	33	8	18	4	11	3	61
Assistive device services	103	24	44	10	21	5	48
Specialist educational services	26	6	12	3	6	1	50
Vocational training	70	16	37	9	22	5	59
Counselling for person with a disability	47	11	31	7	17	4	55
Counselling for parents/family	48	11	26	6	18	4	69
Welfare services	51	12	25	6	9	2	36
General health services	314	73	301	70	277	65	92
Health information	127	30	106	25	89	21	84
Traditional or faith healers	356	83	269	63	254	59	94
Legal advice	49	11	8	2	5	1	63
Specialist health services	40	9	22	5	14	3	64

with disabilities experience ill health as a consequence of their underlying impairment, or because an underlying condition (e.g. diabetes) causes both ill health and impairment. Another possibility, if the association is causal, is that people with disabilities are often poorer, and therefore potentially more vulnerable to ill health. Finally, ageing is also independently related to both disability and poor health.

Our findings are also consistent with previous studies which showed that people with disabilities were not less likely to access care when needed.[2,10] This is a surprising finding, given the widely reported barriers facing people with disabilities in accessing health care.[5–7]

There are several possible explanations. The first is that although people with disabilities face difficulties accessing health, they manage to overcome these barriers to have equal inclusion in health. This may particularly be the case where health services are more readily available. In Cameroon, the large faith-based hospital in the region would have assisted in the provision of free services, and in India the health worker density in the region was considerably larger than the country-wide average.

The second is that equal access amongst people with and without disabilities does not necessarily mean equal service quality or patient experience for people with disabilities compared to those without. Another possibility is that we need to address this question in a more nuanced way. Perhaps when people are seriously ill they will seek care, but that access will be poorer if the condition is less severe. This would be reflected in lower coverage of routine treatments such as treatment for hypertension or diabetes, among people with disabilities. A final possibility is that people with disabilities are in greater contact with health services as a result of their disability, and therefore this enables them to overcome some of the additional barriers that they face and seek when it is needed. More detailed studies are needed in future to explore these possibilities.

In contrast, we found clear evidence that people with disabilities had low awareness of rehabilitation services, and consequently were not often using these services. This is consistent with a previous study undertaken in Haiti.[25] This finding supports the aim of the WHO's Global Disability Action Plan to increase access to rehabilitation services, as well as health services, among people with disabilities.[9] Improving access to rehabilitation services is crucial to allow people with disabilities to achieve their full potential on an equal basis with others. It should therefore be considered an essential component of Universal Health Coverage. A central implication of this study is therefore that awareness and availability of rehabilitation services needs to be increased in both India and Cameroon. Further work is needed to ensure health information is accessible at the community level and to provide clear networks for rehabilitative referral.

Strengths and limitations

This was a large case–control study, conducted using comparable methods in two contrasting settings. Furthermore, we assessed in detail access to health care, as well as rehabilitation and assistive devices. We also used a comprehensive approach to the assessment of disability.

In terms of limitations, whilst participants who screened positive for disabilities were referred to local CBR programmes, we did not investigate access to CBR in the case–control questionnaire. We investigated serious health events, but perhaps should have broadened this to look at other specific measures of morbidity in both settings. We also did not focus on the quality or cost of the care received, which may have differed between people with and without disabilities.

Finally, we relied on self-reported health and activities, rather than observing actual behaviour.

Conclusion

In conclusion, our study showed that people with disabilities are significantly more vulnerable to serious health conditions in India and Cameroon but appeared able to access health care services when these were needed. Awareness and use of rehabilitation services is low and should be increased. We also need to explore in more detail whether people with disabilities are able to access more routine health care, rather than focussing on more serious conditions.

Declaration of interest

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Chapter Ten *Paper Four*: Livelihood Opportunities amongst Adults with Disabilities in Cameroon and India: a case control study

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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

SECTION B – Paper already published

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Stage of publication	**Submitted**

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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)

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Supervisor Signature: [redacted] Date: 30.03.2017

Title: Livelihood Opportunities amongst adults with and without disabilities in Cameroon and India: a case control study

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Abstract

This article provides much needed quantitative evidence on livelihood opportunities amongst adults with disabilities in one African and one Asian Setting. We undertook a population-based case–control study of adults (18+) with and without disabilities in North-West Cameroon and in Telangana State, India. We found that adults with disabilities were five times less likely to be working compared to age-sex matched controls in both settings. Amongst persons with disabilities, current age, marital status and disability type were key predictors of working. Inclusive programmes are therefore needed to provide adequate opportunities to participate in livelihood opportunities for persons with disabilities in Cameroon and India on an equal basis as others.

Keywords: livelihoods, disability, Cameroon, India, participation

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10.1 Introduction

The 2030 Sustainable Development Agenda (SDA) adopted by the United Nations General Assembly in September 2015 asserts that it shall leave no-one behind in its push for social and economic development[33]. As part of the agenda for ending poverty and inequality, 'decent work for all' has been promoted in Sustainable Development Goal Eight as a key tool for promoting inclusive economic development[33]. This rhetoric is of crucial importance in relation to the estimated one billion people living with disabilities globally, 80% of whom live in low and middle income countries (LMIC) [2, 185].

Persons with disabilities are defined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as those 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'[31]. Disability was largely absent from the international development agenda set by the precedent 2000-2015 Millennium Development Goals, which arguably led to persons with disabilities being excluded from development efforts and widening the poverty gap between people with and without disabilities [186-188]. In response to criticism on this issue, the 2030 SDGs have placed a greater emphasis on inclusive development, with calls for tracking equity in progress in meeting all of its goals through disaggregation of data by disability.

Poverty and disability are interlinked; a recent systematic review found a positive association between disability and economic poverty in 80% of the 78 included studies[189]. The relationship between poverty and disability is theorized as cyclical [190, 191]. Poverty is posited to increase the risk of disability via exclusion from health care or health information, and through heightened exposure to risk factors for poor health and impairment (including trauma, infectious disease, unsafe environments, poor sanitation and malnutrition) [60, 65]. Conversely, disability can lead to or exacerbate poverty through participation restrictions, including exclusion from education, and barriers to engaging in decent work [56]. Exclusion from

livelihood opportunities has also been shown to negatively impact on psychosocial wellbeing, identity and social inclusion [192].

Livelihoods can be defined as the means through which individuals or households are able to meet their basic needs. It encompasses not only remunerated labour, but also an individual's capabilities (e.g. level of education, skills), assets and participation in other productive activities (e.g. farming for direct consumption)[54]. Building upon this definition, the Sustainable Livelihood Approach promotes the idea that for a livelihood to be sustainable, individuals must be able to both maintain a basic standard of living through times of stress and shock (e.g. natural disasters, economic upheaval) and to have opportunities for livelihood improvement (e.g. through education and productive investments). The Sustainable Livelihood Approach has been a fundamental cornerstone to international development and poverty reduction, as it emphasizes a shift beyond the subsistence level, toward long-term poverty alleviation. A key component for sustainable livelihoods is engagement in decent work: work that is stable, respects an individual's dignity, provides safe conditions and fair remuneration.

Persons with disabilities are believed to face widespread exclusion from livelihood opportunities. While there is clear evidence from high-income countries of a gap in employment rate between people with and without disabilities – averaging 40% of the rate of people without disabilities – equivalent analyses from LMICs are more challenging given the complexity of livelihood situations in many of these settings [193-195]. Notably, in many LMICs the vast majority of the labour force participates in the informal economy, in subsistence agriculture, or in economic activities that are often not monitored and difficult to measure [55]. Still, existing evidence points to substantial inequalities: for example, in the 2002-2003 World Health Surveys significant employment gaps between people with and without disabilities were found across nine of 15 LMICs, with people with multiple impairments and men experiencing the highest gaps[50]. Lower rates of employment among persons with disabilities have been found consistently in other studies, though many focus on formal sector employment only[196, 197].

Considering the over-representation of persons with disabilities amongst the poor[198] and the SDA's focus on decent work for all as a tool for inclusive economic development, there is an urgent need for data on access to livelihood opportunities amongst persons with disabilities. Understanding this relationship is key if the focus on inclusive development and elimination of poverty within the SDGs is to be achieved.

The aim of this study was to build evidence on access to livelihoods amongst adults with and without disabilities in Cameroon and India.

10.2 Methods

10.2.1 Study Overview

We undertook all-age population-based surveys of disability in Cameroon and India. Disability was conceptualised as per the World Health Organisation's (WHO) bio-psycho-social International Classification of Functioning, Disability and Health (ICF), which perceives disability as an umbrella term incorporating difficulties in any one of three inter-related spheres of functioning – impairments, activity limitations or participation restrictions – as the result of an interaction between a health condition and contextual factors[199]. We used both a self-reported functioning tool and clinical screening tools to identify individuals with disabilities.

A case-control study of people with and without disabilities was nested within the population-based study to assess the impact of disability on livelihoods and wellbeing.

10.2.2 Study Setting

The study took place in Fundong Health District, North West Cameroon in 2013, and in Mahabubnagar District, Telangana State in India in 2014. Cameroon is ranked 153rd and India 131st in the 2016 Human Development Index (HDI), and

approximately a quarter of the population in both countries live below $1.25 per day [200].

10.2.3 Survey Population and Sampling

We conservatively estimated the all-age prevalence of disability to be four percent in both India and Cameroon[2, 41]. This required a sample of 4,056 per country, assuming precision of 20%, 95% confidence, a design effect of 1.4 and 20% non-response.

In each setting, we selected 51 primary sampling units (clusters) from the most recent National Census using probability proportionate to size sampling. Within clusters, modified compact segment sampling was used[201]. A cluster sketch map was created by enumerators, together with local leaders, and divided into segments of approximately 80 people. One segment was randomly selected, and all households within this segment were visited door-to-door until 80 people of all ages were enumerated.

Eligible household members were informed about the survey and invited to attend a local, central location for screening over the following two days. Enumerators made two repeat visits as needed to encourage attendance and those physically unable to attend (e.g. due to mobility impairment) were visited by the survey team in their homes at the end of the second day.

10.2.4 Screening for disability

Participants were screened for i) self-reported functional limitations and ii) clinical impairments in vision, hearing and the musculoskeletal system, epilepsy and depression. Epilepsy as a health condition was included due to the documented association between epilepsy and health-related quality of life, and between seizure-related falls and long-term physical impairment [119]. The screening tools and protocols for adults (18 and above) are described below [202].

Self-reported limitations:

The Washington Group Extended Set on Functioning for Adults was used to screen for self-reported functional limitations. This is comprised of 21 questions about level of difficulty with functioning scored on a severity scale of no difficulty, some difficulty, a lot of difficulty and cannot do [71].

Vision Impairment:

We assessed visual acuity (VA) using a tumbling 'E' chart with size 6/18 optotype on one side and 6/60 on the other[203]. Visual impairment was categorised using the WHO protocol for VA in the better eye: moderate VA <6/18; severe VA <6/60 and >3/60; blind VA <3/60.

Hearing Impairment:

Hearing impairment was measured using a modified version of the WHO Ear and Hearing Disorders Survey Protocol[78]. All participants were first tested using an otoacoustic emissions (OAE) machine for middle ear function. All participants who failed this test in both ears, or for whom an OAE reading could not be taken, underwent Pure Tone Audiometry testing using a field audiometer. Hearing thresholds were recorded as the average threshold across four test frequencies (1KHz, 2KHz, 4KHz and 0.5KHz) and categorised as per WHO recommendations for hearing thresholds in A-weighted decibels (dBA) for the better ear: moderate 41-60 dBA; severe 61-80 dBA; profound >80 dBA.

Musculoskeletal Impairment and epilepsy:

Musculoskeletal impairment and epilepsy were both assessed using the Rapid Assessment of Musculoskeletal Impairment protocol[97].This comprises six preliminary screening questions on a) difficulty using the musculoskeletal system b) use of a mobility aid c) whether a body part was considered misshapen by the participant and d) past experience of seizures. In India, an additional screening

question on chronic back pain was added. Any participant responding affirmatively to one or more question was examined by an Orthopaedic Clinical Officer (Cameroon) or physiotherapist (India), including standardised observation of activities and history to determine the presence of moderate or severe physical impairment and/or epilepsy.

Clinical depression:

Clinical depression was measured using the Patient Health Questionnaire (PHQ-9), previously validated in both settings[204]. All participants answered three initial screening questions, with a further six questions triggered based on affirmative response. A composite score of 20 or above signifies symptoms of severe depression.

10.2.5 Defining disability

For the purposes of this study, participants were considered to have a disability if they met any of the following criteria:

- Self-reported functional limitations: 'A lot of difficulty' or 'cannot do' in any basic activity domain (seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care, upper body strength and fine motor dexterity).
- Vision Impairment: presenting vision in better eye of <6/18
- Hearing Impairment: Presenting average hearing threshold in better ear of >40dBA
- Musculoskeletal Impairment: structure impairment with moderate effect on the musculoskeletal system's ability to function as a whole 25-49% or greater
- Epilepsy: three or more tonic clonic seizures previously experienced
- Depression: score of 20 or above on PHQ-9

10.2.6 Nested Case-Control Study

All participants aged 18 and above who screened positive for disability were invited to participate in the nested case-control study alongside an age (+/- five years), gender and cluster-matched control. One additional adult with a disability was identified through community key informants (e.g. local health workers) from an adjacent segment in each cluster to ensure adequate sample size for the case-control study.

Cases and controls were interviewed using a standardised questionnaire including modules on: socio-economic status, education, healthcare and rehabilitation, participation and environmental barriers, water and sanitation as well as livelihoods, which is the focus of this paper. The livelihoods module assessed engagement in work in the last 12 months, type of work (including informal work seasonality and type of payment), reasons if not working and access to both state and non-state livelihood support. Questionnaires were translated into local languages using standard forward and backward translation procedures and were pilot tested in each setting.

10.2.7 Training

Three teams per setting received ten days training. Teams were comprised of two interviewers, two enumerators, three field assistants, one audiologist/ENT nurse, one ophthalmic nurse/vision tech and one physiotherapist/orthopaedic clinical officer

10.2.8 Data Entry and Analysis

All screening data were double-entered into a purpose-built Microsoft Access Database. The case-control questionnaire was built using Open Data Kit software and administered using ASUS Google Nexus 7 android tablets. Data were analysed in STATA 12.0.

The primary outcome variable 'working' was defined as having undertaken any activities contributing to household consumption (inclusive of subsistence farming and remuneration for any activity in cash or kind).

Six binary, non-mutually-exclusive, variables for 'type' of disability were constructed based on a combination of the clinical and self-reported results.

These were:

- Vision: VA<6/18, or reported 'a lot of difficulty' or 'cannot do' in the vision domain of the WG questions
- Hearing: Presenting average hearing threshold in better ear of >40dBA, or reported 'a lot of difficulty' or 'cannot do' in the hearing domain of the WG questions
- Physical Function: Structure impairment of 25-49% or greater, screens positive for epilepsy, or reported 'a lot of difficulty' or 'cannot do' in the physical domain of the WG questions
- Intellectual Function: Reported 'a lot of difficulty' or 'cannot do' in the learning and understanding domains of WG questions
- Depression: score of 20 or above on PHQ-9
- Multiple: More than one of the above.

Severity of limitation was calculated amongst cases as 'moderate' or 'severe/profound' based on severity combined across both the participant's reported functional limitation responses (with 'a lot of difficulty' corresponding to moderate, 'cannot do' as severe) and clinical impairment severity as per the international protocols described above.

We constructed a socio-economic status (SES) score through principal component analysis (PCA) of household assets [205]. The PCA score distribution amongst controls was used to define the interquartile range, with cases then categorised into quartiles based on control 'cut-points'[183].

We undertook logistic regression analyses adjusted for age and sex to a) compare participation in work between cases and controls stratified by age, sex, SES, marital status and education and b) to explore socio-demographic and clinical predictors of working amongst cases. We also undertook multivariate logistic regression analyses for the above relationships, incorporating all above variables in the model to adjust for potential confounders. Binary variables were created for marital status (married versus never married, widowed or divorced) and education (no education versus at least one year of education). Conditional logistic regression was not conducted since complete matching was not achieved. The 'vce' command was used to calculate robust standard errors accounting for the heteroscedasticity of the sample in relation to clustering.

10.2.9 Ethical Considerations

Ethical Approval for the study was provided by:

- The London School of Hygiene and Tropical Medicine (London, UK)
- National Ethics Committee for Research in Human Health (CNERSH, Cameroon)
- Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon)
- Indian Institute of Public Health Hyderabad Institutional Ethics Committee (India)
- Government of India Health Ministry Screening Committee (India)

Informed written/finger-print consent was obtained from all participants. Participants identified in the screening to have vision, hearing or musculoskeletal impairments were examined by the relevant clinical team members to determine cause and referral needs. Clinical team members also distributed basic medicines where appropriate and all participants with unmet health or rehabilitative needs were referred to relevant services.

10.3 Results

10.3.1 Study population

In India, the sample comprised 441 adult cases (378 identified via the survey and 63 through case-finding) and 288 age and gender matched controls. In Cameroon, 315 adult cases (271 identified via the survey and 44 via case-finding) and 184 controls were identified. The total number of controls is lower than the number of cases in both settings due to high prevalence of disability in older adults, limiting the availability of eligible controls in this age group.

Cases were well matched to controls on gender in both settings, but were more likely to be in the oldest age category (66+) in both India (OR=5.3, 95%CI= 3.2 – 8.9) and Cameroon (2.9, 1.9 – 4.4) (Table 1). Low levels of education and literacy were observed in both sites, with no differences between cases and controls. Cases in India were more likely to be in the poorest socio-economic quartile than controls (1.6, 1.1 – 2.4) but there were no differences in Cameroon. In both settings persons with disabilities were much more likely to have never married (India: 2.6 (1.3 – 5.3), Cameroon: 3.6 (1.6 – 8.3).

Among persons with disabilities, the distribution of 'type' of disability experienced was similar in both countries. Physical limitations accounted for the highest proportion of disability in both samples (55% of cases in India and 60% in Cameroon), followed by sensory limitations (vision 39%, hearing 40% in India, vision 34%, hearing 38% in Cameroon), intellectual limitations (15% and 19% respectively) and depression (9%, 3%). One third of persons with disabilities experienced multiple limitations. Due to case-finding, these do not constitute prevalence estimates or population-reliable proportions, whilst prevalence estimates from the population-based survey are reported elsewhere[206].

Amongst persons with disabilities, reported age of onset was lower in India than Cameroon (41% within the first five years of life in India, compared with 15% in Cameroon). Mean years of disability experienced was therefore higher in India (27.6, standard deviation 24.6) than Cameroon (17.7, sd 18.9). In India, 56% of

persons with disabilities experienced moderate functional limitations compared with 76% in Cameroon, with the remainder in each setting experiencing severe or profound functional limitation.

10.3.2 Access to livelihoods

Persons with disabilities were substantially less likely to have engaged in work (including informal activities or subsistence agriculture) in the past 12 months compared to people without in both India (82% of controls versus 48% of cases, OR= 0.2, 95% CI = 0.2 – 0.4) and Cameroon (90% versus 69%, 0.3, 02 – 0.5) (Table 2). This relationship remained when stratified by age group, gender, marital status and education level. Persons with disabilities were significantly less likely than people without to work across the SES quartiles with the exception of the second-lowest (poorest) socio-economic quartile in India (0.5, 0.2 – 1.2) and highest (least poor) quartile in Cameroon (0.7, 0.3 – 1.7) where the differences were non-significant.

Amongst study participants that were working, there was no difference in the type of work undertaken (work for self/household business, work for non-household member or work on farm owned/rented by the household) by people with and without disabilities in either setting. In India, persons with disabilities were more likely (2.0, 1.3 – 3.1) to work irregularly (i.e. seasonally/part of the year rather than throughout), and less likely to be paid in a combination of cash funds and in kind than people without disabilities (Table 3). Amongst those working, half (50%) of both people with and without disabilities worked on a farm either owned or rented by the household, compared with over three quarters of both people with and without disabilities in Cameroon.

10.3.3 Predictors of access

Table 4 explores predictors of working amongst persons with disabilities. In India, persons with disabilities aged 34 – 49 (36.3, 15.7 – 83.6) or 50 – 65 (5.8, 3.0 – 11.0) compared to over 65 years, and those who were married (2.3, 1.4 – 4.0), were more

likely to work. Females (0.5, 0.3 – 0.7) and people in the highest socio-economic quartile were significantly less likely to work, while there was no significant association with education. In terms of disability, those who reported onset of disability aged fifty and above (0.3, 0.1 – 0.6) and those experiencing physical limitations (0.4, 0.2 – 0.6) or depression (0.3, 0.1 – 0.7) were the least likely to be working. Similarly, in Cameroon, the likelihood of working amongst persons with disabilities was highest in the age groups of 34 – 49 (3.9, 1.4 – 11.1) and 50 – 65 (2.2, 1.1 – 3.9), and amongst those who were married (2.0, 1.1 – 3.6). There was no relationship between likelihood of working and gender or socio-economic status in Cameroon, but education was positively associated with working (2.0, 1.1 – 3.6). Persons with disabilities in Cameroon were more likely to be working if they acquired their disability in later childhood (aged 5 – 17) compared to under the age of five (3.6, 1.2 – 10.8) and were less likely to be working if they experienced physical limitations (0.4, 0.2 – 0.6) or multiple limitations (0.4, 0.2 – 0.7). People with severe or profound functional limitations were also less likely to work compared to those with moderate functional limitations (0.4, 0.2 – 0.8). These results remained similar with multivariate adjustment (data not shown).

10.3.4 Barriers to livelihoods

There were differences between people with and without disabilities in the reasons for not working ($p<0.001$, Table 5). In both settings, persons with disabilities not working commonly reported ageing (India: 44%, Cameroon: 22%) and their health or disability (India: 35%, Cameroon: 60%) as the primary reason. People without disabilities more frequently reported not working due to undertaking unpaid activities (such as housework) (India: 47%, Cameroon: 37%) and ageing (India: 38%, Cameroon:26%).

10.3.5 Support and Social Protection

In India, persons with disabilities were three times more likely to have access to state-sponsored pension support than people without (3.1, 2.1 – 4.6), but access to non-state livelihoods support mechanisms including self-help groups, microfinance

or cash for work schemes were similar for people with and without disabilities (Table 6). In Cameroon, 96% of the sample did not have access to any state-sponsored benefits, and persons with disabilities were less likely than people without to access non-state livelihoods support (e.g. self-help or microfinance groups run by non-state actors) (0.6, 0.4 – 0.9).

10.4 Discussion

In this two-country study persons with disabilities in both settings were five times less likely to be working compared to age and sex matched controls without disabilities, and this relationship held across age groups, gender, marital status, and education level. Among persons with disabilities, key predictors of working were current age, marital status and disability type, however even in the oldest age group of 65 and above, persons with disabilities were substantially less likely to be working than people without disabilities.

The evidence of substantially lower participation in work among persons with disabilities compared to their non-disabled peers in this study corroborates the limited literature on the negative relationship between disability and access to livelihoods in LMICs [56, 140, 207]. This reinforces the theorized pathway to poverty via barriers to work for persons with disabilities and their families and is contrary to Article 27 of the UNCRPD on the right of persons with disabilities to work on an equal basis as others[31].

Overcoming the gap in access to livelihoods between people with and without disabilities is essential in view of the international mandates put forward by the SDA and UNCRPD. Labour market analyses in high-income countries have highlighted numerous components underpinning the employment gap between people with and without disabilities. These include employer misconceptions on the productive capacity of persons with disabilities, insufficient environmental or physical accommodations to the individual's needs, and increased reservation wages (the lowest wage at which a person will work) affected by unbalanced benefit policies

that may dis-incentivise persons with disabilities to join or remain in the labour market[193, 194]. Such dimensions are less well explored/understood in LMIC and in the context of more complex livelihood mechanisms. A qualitative study by Palmer et al. (2015) in Vietnam cited low educational attainment and discrimination as the biggest barriers to both formal and informal work for persons with disabilities [208].

Possible mechanisms for promoting greater participation of persons with disabilities in livelihoods include improved access to social protection systems, healthcare, rehabilitation and assistive devices, education and vocational training [209, 210]. Furthermore, Article 2 of the UNCRPD outlines key obligations of governments to ensure equal opportunities for decent work. These commitments include establishing anti-discrimination laws, ensuring the accessibility of workplaces and, together with employers, providing reasonable accommodations to workers with disabilities[67]. However, evidence on both the availability and impact of these different interventions on improving access to livelihoods for persons with disabilities in LMICs is extremely minimal, and in urgent need of prioritisation [200].

Persons with disabilities were slightly more likely to be in the poorest socio-economic quartile in India, but in Cameroon, no differences in socio-economic status between groups was observed. This contrasts to prevailing literature that have shown association between livelihoods and poverty, but is similar to findings shown in Afghanistan, Zambia and Rwanda[79, 211]. Reasons are unclear, but may reflect very high levels of poverty across the population making it more difficult to detect differences between groups. Similarly, it exposes the need to explore more nuanced measures of multidimensional poverty incorporating additional dimensions such as living standards and empowerment, in addition to measures of economic poverty.

The similarity in education and literacy levels between cases and controls in both settings, while seemingly contrasting to the growing evidence on the widespread exclusion of children with disabilities from school [51] should be interpreted in light of age of onset of disability. The majority of cases (51% in India and 77% in Cameroon) reported disability onset beyond school age. This serves as a reminder

of the need to be cognisant of the potentially varying implications of disability as acquired at different time-points in the life-cycle.

Exploring predictors of access to livelihoods amongst persons with disabilities highlighted additional trends and the heterogeneity in the lived experience of disability. The finding that in India, women with disabilities were twice as likely not to be working as men with disabilities, supports the theorized 'double discrimination' experienced by women with disabilities [212, 213]. In contrast, in Cameroon no difference was observed between genders. This may be related to the high proportion of both cases and controls working in agrarian livelihoods in Cameroon (77%, compared with 50% in India), which may be less vulnerable to external stigma than those seeking livelihood opportunities through an employer or customer-facing business.

Our study found that marital status was strongly associated with disability and access to livelihoods. First, persons with disabilities were less likely to be married than people without disabilities in both settings, which supports previous literature on disability stigma and societal misconceptions of asexuality of persons with disabilities [185, 214]. Second, among persons with disabilities, those who were married were more likely to work even after adjustment for confounders. This may be related to the psychological benefits of cohabiting with a partner, as opposed to being single, widowed or divorced, which has long been established to build human and social capital, improve psychological wellbeing and provide resilience [215]. Conversely, the reverse causality may hold, in that there is increased likelihood of marriage amongst persons with disabilities who work. Further, ideally longitudinal, research is needed in this area.

Age of onset and type of functional limitation affected likelihood of access to livelihoods in different ways in the two settings. In terms of onset, amongst persons with disabilities, those who had acquired their disability aged fifty and above in India, and below five years of age in Cameroon were the least likely to be working. Physical limitations were associated with lower likelihood of working in both settings, alongside depression in India, and the presence of multiple limitations in

Cameroon. As over half of persons with disabilities that worked in India and three quarters in Cameroon were small-scale farmers, the inherently physically-demanding nature of the predominant livelihoods may explain why those with physical limitations in each setting were less likely to work. The finding that people with depression were least likely to be working in India is in line with findings from a systematic review highlighting a strong association between common mental disorders and poverty – including but not restricted to economic poverty and employment – in LMICs [64].

Taken in aggregate, these findings substantiate arguments related to the heterogeneity of disability and the lived experiences of persons with disabilities, and highlights the importance of disability data disaggregation in research findings[193, 216, 217]. Moreover, in relation to the Sustainable Development Agenda, it necessitates responsiveness and reactivity even within the context of inclusive programme design to meet diverse needs, capacities and environmental contexts, and break down the barriers to engaging in sustainable livelihoods experienced by persons with disabilities in different contexts and settings.

The relatively high proportion of persons with disabilities receiving state-sponsored livelihood support in India, and non-state support in Cameroon, is encouraging, particularly in light of the evolving discourse and evidence related to social protection as a mechanism for mitigating and preventing poverty. Social protection will be most transformative when it addresses drivers of poverty and barriers to decent work, such as poor access to timely, affordable healthcare and quality education; however, the nature and impact of state and non-state supports in these contexts was not a focus of this research. The role of social protection in reducing poverty and improving livelihoods is a complex and nuanced research area, which deserves further attention in future studies[218].

10.4.1 Strengths and Limitations

Our primary dependent variable 'working' is a relatively narrow conceptualisation of livelihoods, and may miss some of the multiple productive activities that

households and individuals may engage in, particularly in rural and informal economies [219-221]. Moreover, we are limited in our analyses by the cross-sectional nature of the data, despite our attempts to adjust for age of onset in relation to the outcome variables. In addition, the unexpectedly large burden of disability in the older age groups, while an important finding in itself, prevented us from achieving perfect age-sex matching of cases to controls.

In terms of strengths, this was a large population based case-control study in two settings assessing the quantitative relationship between disability and access to livelihoods. We used a comprehensive approach to measuring disability and assessed access to livelihood both between people with and without disabilities, and amongst persons with disabilities.

10.5 Conclusion

This study provides empirical evidence of the exclusion of persons with disabilities from livelihood opportunities in one region each of Cameroon and India. Moreover, the findings highlight the heterogeneity of that exclusion amongst persons with disabilities. This necessitates both adequately disaggregated quantitative data that fully reflects the spectrum of experiences by persons with disabilities in accessing livelihood opportunities, and appropriately reactive inclusive programmes that can meet diverse needs. The coverage of livelihood protective programmes and benefits in both settings was encouraging, and should be promoted within the context of sustainability and access to work

Table 1: Socio-demographic Characteristics of Cases and Controls in India and Cameroon						
	India			Cameroon		
	Cases (n=441) N (%)	Controls (n=288) N (%)	Age & Sex Adj OR (95% CI)	Cases (n=315) N (%)	Controls (n=184) N (%)	Age & Sex Adj OR (95% CI)
Age Group						
18-33	83 (19%)	76 (26%)	Baseline	54 (17%)	45 (25%)	Baseline
34-49	94 (21%)	84 (29%)	1.0 (0.8 – 1.4)	33 (10%)	42 (23%)	0.7 (0.4 – 1.0)
50-65	165 (37%)	111 (39%)	1.4 (1.1 – 1.7)	70 (22%)	51 (28%)	1.1 (0.8 – 1.7)
>65	99 (22%)	17 (6%)	5.3 (3.2 – 8.9)	158 (50%)	46 (25%)	2.9 (1.9 – 4.4)
Gender						
Male	199 (45%)	133 (46%)	Baseline	123 (39%)	70 (38%)	Baseline
Female	242 (55%)	155 (54%)	1.0 (0.9 – 1.2)	192 (61%)	114 (62%)	1.1 (0.8 – 1.6)
Education						
None	322 (73%)	186 (65%)	1.6 (1.0 – 2.7)	195 (62%)	78 (42%)	2.0 (1.0 – 3.9)
Primary	61 (14%)	37 (13%)	1.7 (1.0 – 2.9)	97 (31%)	77 (42%)	1.5 (0.8 – 2.6)
Secondary or higher	58 (13%)	65 (23%)	Baseline	23 (7%)	29 (16%)	Baseline
Literacy[a]						
Can read	124 (28%)	102 (36%)	0.8 (0.6 – 1.2)	113 (36%)	101 (55%)	0.7 (0.5 – 1.0)
Cannot read	317 (72%)	184 (64%)	Baseline	199 (64%)	82 (44.8%)	Baseline
Marital status[a]						
Married/ living together	327 (74%)	239 (84%)	Baseline	170 (54%)	116 (63%)	Baseline
Divorced/ Separated	8 (2%)	7 (2%)	0.7 (0.3 – 1.7)	7 (2%)	7 (4%)	0.7 (0.2 – 2.4)
Widowed	60 (14%)	17 (6%)	1.6 (0.9 – 2.6)	73 (23%)	31 (17%)	1.2 (0.7 – 2.1)
Never married	46 (10%)	23 (8%)	2.6 (1.3 – 5.3)	62 (20%)	29 (16%)	3.6 (1.6 – 8.3)
SES						
1st Quartile (poorest)	155 (36%)	72 (25%)	1.6 (1.1 – 2.4)	78 (25%)	46 (25%)	1.0 (0.5 – 2.0)
2nd Quartile	81 (19%)	72 (25%)	0.8 (0.5 – 1.3)	113 (36%)	46 (25%)	1.6 (0.8 – 3.3)
3rd Quartile	103 (24%)	72 (25%)	1.1 (0.6 – 1.8)	62 (20%)	46 (25%)	0.8 (0.4 – 1.7)
4th Quartile (richest)	95 (22%)	72 (25%)	Baseline	62 (20%)	46 (25%)	Baseline

Disability measure [b]						
Vision	170 (39%)	-	-	108 (34%)	-	-
Hearing	175 (40%)	-	-	120 (38%)	-	-
Physical Function	243 (55%)	-	-	190 (60%)	-	-
Intellectual Function	67 (15%)	-	-	60 (19%)	-	-
Depression	41 (9%)	-	-	8 (3%)	-	-
Multiple	174 (39%)	-	-	115 (36%)	-	-
Disability onset						
Under 5	172 (41%)	-	-	47 (15%)	-	-
Childhood (5 – 17)	36 (9%)	-	-	23 (7%)	-	-
Working age (18 – 49)	78 (19%)	-	-	73 (23%)	-	-
Older age (50 +)	103 (25%)	-	-	125 (40%)	-	-
Unknown	29 (7%)	-	-	43 (14%)	-	-
Functional limitation Severity[c]						
Moderate	223 (56%)	-	-	238 (76%)	-	-
Severe/Profound	182 (44%)	-	-	74 (24%)	-	-

[a]Missing marital status and literacy status for two controls in India, and for three cases and one control in Cameroon

[b] Not mutually exclusive (i.e. sum >100%)

[c]India: 26 severity missing as Epilepsy only cases with no severity scale, 3 missing Cameroon

Table 2 Relationship between disability and working status stratified by age, sex, education and SES (% worked in the last twelve months)						
	India			Cameroon		
	Cases (n=441) N (%)	Controls (n=288) N (%)	Age & Sex Adj OR (95% CI)	Cases (n=315) N (%)	Controls (n=184) N (%)	Age & Sex Adj OR (95% CI)
Total study population	212 (48%)	235 (82%)	0.2 (0.2 – 0.4)	217 (69%)	165 (90%)	0.3 (0.2 – 0.5)
Gender						
Males	111 (56%)	118 (89%)	0.2 (0.1 – 0.4)	87 (71%)	65 (93%)	0.2 (0.1 – 0.6)
Females	101 (42%)	117 (75%)	0.3 (0.2 – 0.5)	130 (68%)	100 (88%)	0.3 (0.2 – 0.6)
Age (years)						
18-33	40 (48%)	56 (74%)	0.3 (0.1 – 0.7)	29 (54%)	40 (89%)	0.1 (0.1 – 0.4)
34-49	79 (84%)	79 (94%)	0.3 (0.1 – 1.1)	29 (88%)	38 (90%)	0.7 (0.2 – 3.3)
50-65	79 (48%)	91 (82%)	0.2 (0.1 – 0.4)	56 (80%)	48 (94%)	0.2 (0.1 – 0.8)
>65	14 (14%)	9 (53%)	0.1 (0.1 – 0.4)	103 (65%)	39 (85%)	0.3 (0.1 – 0.8)
Marital Status						
Married	180 (55%)	207 (87%)	0.4 (0.2 – 0.9)	129 (76%)	109 (94%)	0.3 (0.1 – 0.7)
Not Married	32 (28%)	28 (57%)	0.2 (0.1 – 0.3)	88 (61%)	56 (82%)	0.3 (0.2 – 0.6)
Education						
One or more years education	65 (55%)	80 (78%)	0.2 (0.1 – 0.4)	89 (74%)	95 (90%)	0.4 (0.2 – 0.8)
No education	147 (46%)	115 (83%)	0.3 (0.1 – 0.6)	128 (66%)	70 (90%)	0.2 (0.09 – 0.6)
SES						
1st Quartile (poorest)	79 (51%)	63 (88%)	0.1 (0.05 – 0.4)	50 (64%)	41 (89%)	0.2 (0.08 – 0.6)
2nd Quartile	45 (56%)	56 (78%)	0.5 (0.2 – 1.2)	79 (70%)	44 (96%)	0.1 (0.02 – 0.5)
3rd Quartile	53 (52%)	64 (89%)	0.1 (0.05 – 0.3)	44 (71%)	43 (93%)	0.2 (0.06 – 0.6)
4th Quartile (richest)	30 (32%)	52 (72%)	0.2 (0.07 – 0.4)	44 (71%)	37 (80%)	0.7 (0.3 – 1.7)

Table 3: Relationship between disability and livelihoods						
	India			Cameroon		
	Cases (n=212) N %	Controls (n=233) N %	Age & Sex Adj OR (95% CI)	Cases (n=214) N %	Controls (n=163) N %	Age & Sex Adj OR (95% CI)
Type of work[a]						
Work for self/ household business	18 (8%)	28 (12%)	Baseline	31 (14%)	30 (18%)	Baseline
Work for non household member	88 (42%)	88 (38%)	1.6 (0.8 – 3.2)	18 (8%)	11 (7%)	1.6 (0.7 – 3.6)
Work on farm owned or rented by household	106 (50%)	117 (50%)	1.4 (0.7 – 2.9)	165 (77%)	122 (75%)	0.7 (0.4 – 1.5)
Regularity of work						
Throughout the year	117 (55%)	165 (71%)	Baseline	95 (44%)	84 (52%)	Baseline
Seasonally/ part of the year	88 (42%)	62 (27%)	2.0 (1.3 – 3.1)	99 (46%)	66 (40%)	1.1 (0.7 – 1.9)
Once in a while	7 (3%)	6 (3%)	1.7 (0.6 – 4.9)	20 (9%)	13 (8%)	1.4 (0.6 – 3.3)
Type of payment[a]						
Cash only	166 (78%)	153 (66%)	Baseline	25 (12%)	21 (13%)	Baseline
Cash and in kind	40 (19%)	71 (30%)	0.5 (0.3 – 0.8)	87 (41%)	65 (40%)	0.8 (0.4 – 1.6)
In kind only	4 (2%)	7 (3%)	0.5 (0.1 – 1.6)	42 (20%)	31 (19%	0.8 (0.3 – 1.7)
Not paid	2 (1%)	2 (1%)	-	60 (28%)	46 (28%)	0.7 (0.3 - 1.6)

*missing data on livelihoods for two controls in India, and three cases and two controls in Cameroon, excluded from analysis

[a]Amongst all those working within last 12 months

'-'Omitted due to small cell size

Table 4 Predictors of working in the last twelve months among cases						
	India			Cameroon		
	Working (n=212) N (%)	Not working (n=229) N (%)	Age & Sex Adj OR (95% CI)	Working (n=217) N (%)	Not working (n=98) N (%)	Age & Sex Adj OR (95% CI)
Gender						
Male	111 (52%)	88 (38%)	Baseline	87 (40%)	36 (37%)	Baseline
Female	101 (48%)	141 (62%)	0.5 (0.3 – 0.7)	130 (60%)	62 (63%)	0.9 (0.5 – 1.5)
Age (years)						
18-33	40 (19%)	43 (19%)	5.6 (2.6 – 11.9)	29 (13%)	25 (26%)	0.6 (0.3 – 1.2)
34-49	79 (37%)	15 (7%)	36.3 (15.7 – 83.6)	29 (13%)	4 (4%)	3.9 (1.4 – 11.1)
50-65	79 (37%)	86 (38%)	5.8 (3.0 – 11.0)	56 (26%)	14 (14%)	2.2 (1.2 – 3.9)
>65	14 (7%)	85 (37%)	Baseline	103 (47%)	55 (56%)	Baseline
Marital Status						
Married	180 (85%)	147 (64%)	2.3 (1.4 – 4.0)	129 (59%)	41 (42%)	2.0 (1.1 – 3.6)
Not Married	32 (15%)	82 (36%)	Baseline	88 (41%)	57 (58%)	Baseline
Education						
Educated	65 (31%)	54 (24%)	0.9 (0.4 – 1.7)	89 (41%)	31 (32%)	2.0 (0.9 – 4.2)
Not educated	147 (69%)	175 (76%)	Baseline	128 (59%)	67 (68%)	Baseline
SES						
1st Quartile (poorest)	79 (33%)	79 (38%)	Baseline	50 (23%)	28 (29%)	Baseline
2nd Quartile	36 (16%)	45 (22%)	1.4 (0.7 – 3.1)	79 (36%)	34 (35%)	1.4 (0.8 – 2.4)
3rd Quartile	50 (50%)	53 (26%)	1.0 (0.6 – 1.7)	44 (20%)	18 (18%)	1.4 (0.7 – 2.8)
4th Quartile (richest)	65 (29%)	30 (15%)	0.4 (0.2 – 0.8)	44 (20%)	18 (18%)	1.3 (0.7 – 2.3)
Age of Disability onset						
Under 5	98 (53%)	74 (37%)	Baseline	26 (14%)	21 (26%)	Baseline
Childhood (5 – 17)	12 (6%)	24 (12%)	0.5 (0.2 – 1.6)	19 (10%)	4 (5%)	3.6 (1.2 – 10.8)
Working age (18 – 49)	54 (29%)	24 (12%)	1.1 (0.6 – 2.0)	54 (29%)	19 (24%)	1.4 (0.6 – 3.6)
Older age (50 +)	22 (12%)	81 (40%)	0.3 (0.1 – 0.6)	89 (47%)	36 (45%)	1.6 (0.7 – 3.9)

Disability Type[a]						
Vision	77 (36%)	93 (41%)	1.3 (0.8 – 2.1)	76 (35%)	32 (33%)	1.1 (0.6 – 2.0)
Hearing	84 (40%)	9 (40%)	1.5 (1.0 – 2.4)	79 (36%)	41 (42%)	0.9 (0.6- 1.5)
Physical Function	94 (44%)	149 (65%)	0.4 (0.2 – 0.6)	117 (54%)	73 (74%)	0.4 (0.2 – 0.6)
Intellectual Function	34 (16%)	33 (14%)	0.9 (0.5 – 1.7)	35 (16%)	25 (26%)	0.6 (0.3 – 1.0)
Depression	10 (5%)	31 (14%)	0.3 (0.1 – 0.8)	6 (3%)	2 (2%)	-
Multiple	62 (29%)	112 (49%)	0.6 (0.4 – 1.0)	65 (30%)	50 (51%)	0.4 (0.2 – 0.7)
Functional Limitation Severity[b]						
Moderate	117 (61%)	116 (52%)	Ref.	174 (81%)	64 (65%)	Ref.
Severe/Profound	75 (39%)	107 (48%)	0.8 (0.5 – 1.2)	40 (19%)	34 (35%)	0.4 (0.2 – 0.8)

[a]Non mutually exclusive binary variables

[b]Three missing severity Cameroon; 26 missing severity India excluded from this analysis

Table 5: Primary reason not working amongst those who have not worked at all in the past 12 months

	India				**Cameroon**			
	All (n=282) N (%)	Cases (n=229) N (%)	Controls (n=53) N (%)	p-value	All (n=117) N (%)	Cases (n=98) N (%)	Controls (n=19) N (%)	p-value
Unpaid activities[1]	42 (12%)	17 (7%)	25 (47%)	<0.001	14 (12%)	7 (7%)	7 (37%)	<0.001
Ageing/ retirement	121 (43%)	101 (44%)	20 (38%)		27 (23%)	22 (22%)	5 (26%)	
Health or disability	85 (30%)	80 (35%)	5 (9%)		64 (55%)	59 (60%)	5 (26%)	
Other	34 (12%)	31 (14%)	3 (6%)		12 (10%)	10 (10%)	2 (11%)	

P-value from χ^2 test of association

[1] Unpaid activities: housework/chores or being a students

Table 6: Access to benefits and other livelihoods support						
	India			**Cameroon**		
	Cases n (%)	Controls n (%)	Age and Sex Adjusted OR (95% CI)	Cases n (%)	Controls n (%)	Age and Sex Adjusted OR (95% CI)
	n=441	n=288		n=315	n=184	
State Sponsored Benefits						
Pension	225 (51%)	67 (23%)	3.1 (2.1 – 4.6)	4 (1%)	2 (1%)	1.4 (0.4 – 5.8)
Other benefit	27 (6%)	3 (1%)	11.4 (3.4 – 38.0)	12 (4%)	4 (2%)	2.7 (1.0 – 7.2)
No benefits	189 (43%)	218 (76%)	Baseline	299 (95%)	178 (97%)	Baseline
Non State Livelihoods support						
Any support	106 (24%)	83 (29%)	0.9 (0.6 – 1.3)	146 (46%)	108 (59%)	0.6 (0.4 – 0.9)
Self Help Groups	76 (17%)	64 (22%)	0.8 (0.6 – 1.2)	130 (42%)	89 (49%)	0.7 (0.5 – 1.1)
Microfinance Groups	9 (2%)	6 (2%)	1.2 (0.4 – 3.8)	70 (22%)	53 (29%)	0.8 (0.5 – 1.2)
Cash for Work schemes	42 (10%)	31 (11%)	1.0 (0.5 – 1.8)	42 (13%)	30 (17%)	0.8 (0.5 – 1.5)
Other	1 (1%)	0	-	13 (4%)	5 (3%)	1.7 (0.7 – 4.2)
Binary outcome variables with positive response presented – OR for each variable individually, adjusted for age and sex '-'Omitted due to small cell size						

Chapter Eleven *Paper Five*: Assessing Educational Access and experience amongst children with Disabilities in Cameroon and India

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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 item.

*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?	**International Journal of Educational Development**
Please list the paper's authors in the intended authorship order:	Ms. Islay Mactaggart, Prof. Hannah Kuper, Prof. GVS Murthy, Ms. Jayanthi Sagar, Dr. Joseph Oye, Dr. Sarah Polack
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)

Student Signature: [redacted] Date: 30.03.2017

Supervisor Signature: [redacted] Date: 30.03.2017

Title: Estimating educational access and experience amongst children with and without disabilities in India and Cameroon

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Abstract

Aim: To estimate the association between disability and education amongst children in India and Cameroon.

Methods: We undertook a population-based case–control study of children 5-17 with and without disabilities in North-West Cameroon and in Telangana State, India.

Results: Children with disabilities were between ten (OR=0.1, 95% CI 0.03 – 0.2) and twenty (0.5, 0.02 – 0.2) times less likely to be enrolled than children without disabilities in India and Cameroon respectively, and educational experience was generally worse in both settings.

Conclusion: Evidence-based inclusive education policies and programmes are urgently needed to provide quality education to children with disabilities in India and Cameroon

Keywords: inclusive education; children with disabilities; Cameroon; India

11.1 Introduction

All children have a right to education, as mandated in numerous binding international legislative treaties, including the United Nations Convention on the Rights of the Child (Article 28), the United Nations Convention on Persons with Disabilities (Article 24) and The Universal Declaration of Human Rights (Article 26)[31, 222, 223]. Moreover, an emphasis on access to *quality education* for all children is dictated within the recently agreed Sustainable Development Agenda (SDA), the framework that will guide international development priorities until 2030 [33]. Specifically, the Education 2030 Framework for Action purports to ensure "*inclusive and equitable quality education and lifelong learning opportunities for all*" and was adopted by 184 United Nations Member States at a high level meeting of the United Nations Educational, Scientific and Cultural Organisation (UNESCO) in November 2015 [224]. The last twenty years have also seen the emergence of several landmark education initiatives, including the World Conference on Education for All in 1990, and the Inclusive Education movement reinforced by the Salamanca Framework in 1994, which encourages governments not to segregate education for children with special needs [225].

Despite this formidable legal and political legacy, a small but robust peer-reviewed literature, and a more extensive grey literature, suggests continued, consistent, exclusion from education for children with disabilities, particularly in low and middle income countries (LMICs) [226]. People (inclusive of children) with disabilities are defined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as those 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*"[31]. Filmer (2008) reviewed fourteen nationally representative household surveys across twelve countries, determining that children with disabilities were customarily substantially less likely to be enrolled than their peers [227]. Similarly, Kuper at al. (2014) analysed a database of almost 800,000 children in thirty countries, reporting that children with disabilities were between five and twenty

times less likely to be enrolled in twenty-three of the included countries than children without disabilities [51].

The positive implications of education on an individual's life-course are extensively documented; income increases by up to ten percent per additional year of schooling, learning can promote healthier practices and lower maternal deaths, and bolsters economic growth[228]. Moreover, given the cyclical, mutually reinforcing relationship between disability and poverty, the relative gains of education for children with disabilities are posited to be even higher than other children in terms of incremental increases in income, productivity and economic independence [191, 229, 230].

Multiple potential barriers may converge to limit children with disabilities' access to education. These include physical inaccessibility of the school and built environment, availability of appropriate resources, the attitudes and knowledge of teachers, peers and other adults, and stigma[226].

The relative dearth of peer-reviewed literature on access to, and quality of, education for children with disabilities in LMICs is of concern. This evidence base is crucial for policy makers to plan and finance appropriate, inclusive education systems that meet the needs of all children.

The aim of this study was to assess educational access and experience amongst children with and without disabilities aged five to seventeen in one district each of India and Cameroon.

11.2 Methods

11.2.1 Study Overview

We undertook an all-age population-based survey of disability in one district each of Cameroon (2013) and India (2014). The World Health Organisation (WHO)'s bio-

psycho-social International Classification of Disability, Functioning and Health (ICF) was used as the theoretical framework for conceptualising disability within the study. Disability is defined as an umbrella term integrating difficulties in any one of three inter-related spheres of functioning – impairments, activity limitations or participation restrictions – as the result of an interaction between a health condition and contextual factors [18]. We used both a self-reported functional limitation tool and a number of clinical impairment screening tools to identify children with disabilities in a population-based survey. A case-control study was nested within the population-based survey to assess access to and experience of education for children with disabilities compared to children without disabilities.

11.2.2 Study Settings

Data was collected in Fundong Health District, North West Cameroon, and Mahbubnagar District, Telangana State in India. The 2016 Human Development Index ranks Cameroon 153rd and India 131st, with approximately a quarter of the population in both countries live below $1.25 per day[164].

11.2.3 Survey Population and Sampling

We conservatively estimated an all-age prevalence of disability of 4% in both settings [2, 41]. This required an all-age sample of 4,056 per country, assuming precision of 20%, 95% confidence, a design effect of 1.4 and 20% non-response.

In each setting, 51 primary sampling units (clusters) were selected from the most recent national Census via probability proportion to size sampling. Within clusters households were selected using modified compact segment sampling [201]. Using cluster sketch maps created by enumerators in collaboration with local leaders, clusters were divided into segments of approximately eighty people. One segment was selected at random and all households were visited door-to-door until 80 people of all ages had been enumerated. Two additional children with disabilities and one additional adult with a disability were identified per cluster via key informants (such as community health workers) to ensure sufficient sample size for

the case–control study. These participants were selected from outside the segment sampled for inclusion in the population-based survey but within the same cluster.

Eligible household members were informed about the survey and invited to attend a central community location for screening over the following two days. Up to two repeat visits were made by enumerators to encourage attendance. Those unable to attend (e.g. due to mobility restriction) were visited in their homes by the survey teams.

11.2.4 Screening for disability

Participants were screened using a reported functional limitation tool and a battery of tools to identify clinical impairments in vision, hearing, and the musculoskeletal system, and for epilepsy. Epilepsy was included based on the association between epilepsy and health-related quality of life, and through the relationship between seizure-related falls and physical impairment[119]. The disability screening tools and protocols for children 5 to 17 are described below.

Reported functional limitations

The draft Washington Group/UNICEF Module on Child Functioning and Disability was used to screen for reported functional limitations in children 5 – 17, with permission from the tool's developers[45, 231]. The module includes both basic (seeing, hearing, walking, self-care, understanding, being understood, learning and remembering) and complex (feeling worried/sad, controlling behaviour, completing a task, accepting change, getting along with other children and playing) domains, scored predominantly on a Likert scale of 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'cannot do'. The domain of feeling worried/sad was scored on an alternate Likert scale of 'the same or less', 'more', or 'a lot more' than other children of the same age.

Vision impairment

Visual Acuity (VA) was measured for all children 5 – 17 using a tumbling 'E' chart with size 6/18 optotype on one side and 6/60 on the other [203]. Visual impairment was categorised using the WHO protocol for VA in the better eye: moderate vision impairment <6/18; severe <6/60 and >3/60; and blind <3/60.

Hearing Impairment

Hearing impairment was assessed using a modified version of the WHO Ear and Hearing Disorders Survey Protocol[78]. First, Otoacoustic emissions (OAE) were recorded for all children 5-17 years to determine middle ear function using an OAE machine. All participants who either failed this test in both ears or for whom an OAE reading could not be taken (e.g. due to child discomfort) then underwent Pure Tone Audiometry testing using a field audiometer. A Pure Tone Average (PTA) for each ear was recorded as the mean threshold across 1KHz, 2KHz, 4KHz and 0.5KHz and categorised in A-weighted decibels (dBA) for the better ear as moderate hearing impairment 35-60 dBA, severe 61-80 dBA and profound >80 dBA [48].

Musculoskeletal impairment and Epilepsy

Both musculoskeletal impairment (MSI) and Epilepsy were assessed using the Rapid Assessment of MSI protocol [96]. Six preliminary screening questions related to difficulty using musculoskeletal system and seizure history were posed to all participants, including use of a mobility aid or whether a body part was considered misshapen. In India, a seventh question on chronic back pain was added. Any participant reporting affirmatively to at least one question was examined by an Orthopaedic Clinical Officer (Cameroon) or physiotherapist (India), incorporating a standardised observation of activities and history to determine the presence of any mild, moderate or severe MSI, and/or Epilepsy.

11.2.5 Defining disability

For the purposes of this study, participants were considered to have a disability if they met any of the following criteria:

- Self-reported functional limitations: 'A lot of difficulty' or 'cannot do' in any basic activity domain (seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care).
- Vision Impairment: presenting VA in better eye of <6/18
- Hearing Impairment: presenting PTA in better ear of >35dBA
- Musculoskeletal Impairment: structure impairment with moderate effect on the musculoskeletal system's ability to function as a whole (25-49%) or greater
- Epilepsy: three or more tonic clonic seizures previously experienced

11.2.6 Nested Case-Control Study

All children aged 5-17 who screened positive for disability ('cases') were invited to participate in a nested case-control study alongside a cluster, age (+/- 2 years) and gender matched child without a disability ('control'). In each cluster two additional children aged 5 – 17 with disabilities were identified via community key informants (e.g. local health workers) from an adjacent segment to ensure adequate sample size for the case-control study, and a control was selected for each of these cases.

Children with and without disabilities were interviewed using a standardised questionnaire comprising modules on household socio-economic status, education, livelihoods, healthcare and rehabilitation, participation and environmental barriers, and water and sanitation. The education module consisted of questions related to the child's current and previous enrolment status, educational attainment and absence, participation in school and access to water and sanitation facilities [179]. This paper focuses on the education and water and sanitation modules of the case-control study.

11.2.7 Caregiver versus self-report

In each tool requiring reported response, caregivers reported for children aged 5 – 7 years or unable to communicate independently (e.g. due to communication impairments), whilst children aged 8 – 17 and able to communicate independently responded via self-report in the presence of their primary caregiver.

11.2.8 Training

Three teams per setting received ten days training. Teams were comprised of two interviewers, two enumerators, three field assistants, one audiologist/Ear Nose and Throat nurse, one ophthalmic nurse/vision technician and one physiotherapist/orthopaedic clinical officer.

11.2.9 Data Entry and Analysis

All screening data was double-entered into a purpose-built Microsoft Access Database. The case-control questionnaire was built using Open Data Kit software and administered using ASUS Google Nexus 7 tablets.

Data were analysed in STATA 14.1. We constructed a socio-economic status score through principal component analysis (PCA) of household assets [205]. The PCA score distribution for controls was used to define the interquartile range, with cases then categorised into quartiles based on control 'cut-points' [183].

Six binary, non mutually-exclusive, variables for 'type' of disability were constructed based on a combination of the clinical and self-reported results.

These were:

- Vision: VA<6/18, or reported 'a lot of difficulty' or 'cannot do' in the vision domain of the WG questions
- Hearing: Presenting average hearing threshold in better ear of >35dBA, or reported 'a lot of difficulty' or 'cannot do' in the hearing domain of the WG questions

- Physical Function: Structure impairment of 25-49% or greater, screens positive for epilepsy, or reported 'a lot of difficulty' or 'cannot do' in the physical or self-care domains of the WG questions
- Intellectual Function: Reported 'a lot of difficulty' or 'cannot do' in the domains of understanding, being understood, remembering and concentrating in the WG questions
- Multiple: More than one of the above.

Functional limitation was calculated amongst cases as 'moderate' or 'severe/profound' based on maximum limitation severity combined across both the participant's reported functional limitation responses and clinical impairment severity.

Descriptive analyses were undertaken to describe the age range, sex and socio-economic status of the cohort, alongside attributes of disability amongst children with disabilities (disability type, age of onset and severity). We undertook logistic regression analyses adjusted for age and sex to compare a) current enrolment b) current and repeated grades c) school absences and d) school participation between children with and without disabilities. Conditional logistic regression was not attempted since perfect matching was not achieved. Descriptive analyses only were undertaken to describe attributes (e.g. previous school attendance and barriers to attendance) of children with disabilities out of school given the low quantity of children without disabilities in this group. Amongst children with disabilities, we undertook age and sex adjusted multivariate regression to explore predictors of current school enrolment including age group, sex, socio-economic status, type of disability, age of onset and severity of limitation. Finally, we undertook multivariate logistic regression analyses for the above relationships, incorporating all socio-demographic and disability factors in the model to adjust for potential confounders. The 'vce' command was used to calculate robust standard errors accounting for the heteroscedasticity of the sample in relation to clustering.

Following Mizunoya et al.(2016)'s methodology, the attendance gap between children with and without disabilities was calculated as the percentage point

difference between the percentage of children with disabilities out of school and the percentage of children without disabilities out of school [52].

The Participation Restriction module consisted of 9 items rated using Likert scale response (always, sometimes, never)[179]. We created a binary variable of always versus sometimes and never, and calculated an average total summated score and scores for three sub-scales: Inclusive school environment (items on teacher support, inclusion in lessons and school and accessible learning materials); Peer support (support from friends, friends coming to you for support, friends to play with and friends looking to you as leader); and Experience of violence (violence inflicted by teachers or peers). 'Don't Know' responses were converted to missing data and excluded from analyses related to the relevant item/sub scale. Cronbach's alpha (α) of internal consistency was calculated for each sub-scale and the total scale to assess internal consistency was of an acceptable level ($\alpha \geq 0.7$) as per guidelines for scale reliability [184].

11.2.10 Ethics and Consent

Ethical Approval for the study was provided by:

- The London School of Hygiene and Tropical Medicine (London, UK)
- National Ethics Committee for Research in Human Health (CNERSH, Cameroon)
- Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon)
- Indian Institute of Public Health Hyderabad Institutional Ethics Committee (India)
- Government of India Health Ministry Screening Committee (India)

Informed written/finger-print consent was obtained from primary caregivers for all children in the study, and caregivers remained present throughout the duration of the interview. Children identified in the screening to have vision, hearing or musculoskeletal impairments were examined by the relevant clinical team members

to determine cause and referral needs. Clinical team members also distributed basic medicines where appropriate and all children with unmet health or rehabilitative needs were referred to relevant services.

11.3 Results

11.3.1 Study Population

In India, the sample comprised 67 children with disabilities (24 identified via the survey and 43 identified via case-finding) and 48 children without disabilities. In Cameroon, 114 children with disabilities (60 via the survey and 54 via case-finding) and 90 children without were included. The total number of children without disabilities is lower than children with disabilities. This was because the high prevalence of disability in older adults limited eligible child 'control' households in each cluster as we did not select controls from the same households as cases.

Children with and without disabilities were well-matched by age group and sex in both settings, and there were no observed differences in household socio-economic status (SES) (Table 1). In both India and Cameroon, the highest proportion of children with disabilities had physical functional limitations (India 79% of children with disabilities, Cameroon 59%) whilst over half (India 55%, Cameroon 52%) experienced intellectual limitations. Over half of children with disabilities in each setting (India 55%, Cameroon 54%) reported that they had acquired their limitations at birth, with proportions generally diminishing with age. Approximately two thirds of children with disabilities in India (61%) and one third in Cameroon (37%) experienced severe or profound limitations. Due to case-finding, these do not constitute prevalence estimates. The prevalence of disability amongst children 0-17 obtained in the wider-study within which this research is situated was 4.7% in Cameroon and 3.6% in India [206].

Table 1: Socio-demographic Characteristics of Cases and Controls in India and Cameroon						
	India			Cameroon		
	Cases (n=67) N (%)	Controls (n=48) N (%)	Age and sex adjusted OR (95% CI)	Cases (n=114) N (%)	Controls (n=90) N (%)	Age and sex adjusted OR (95% CI)
Age Group						
5-8	26 (39%)	17 (35%)	Ref.	34 (30%)	31 (34%)	Ref.
9-12	22 (33%)	16 (33%)	0.9 (0.4 – 1.7)	32 (28%)	27 (40%)	1.1 (0.6 – 2.0)
13-17	19 (28%)	15 (31%)	0.8 (0.4 – 1.7)	48 (42%)	32 (36%)	1.4 (0.9 – 2.1)
Gender						
Male	36 (54%)	29 (60%)	Ref.	56 (49%)	43 (48%)	Ref.
Female	31 (46%)	19 (40%)	1.3 (0.9 – 2.0)	58 (51%)	47 (52%)	0.9 (0.7 – 1.2)
Household SES						
1st Quartile (poorest)	16 (24%)	13 (27%)	0.6 (0.2 – 1.9)	37 (32%)	21 (23%)	1.9 (0.8 - 4.6)
2nd Quartile	21 (31%)	12 (25%)	0.9 (0.4 – 2.0)	38 (33%)	24 (27%)	1.7 (0.6 – 5.0)
3rd Quartile	7 (10%)	12 (25%)	0.3 (0.1 – 1.0)	19 (17%)	23 (26%)	0.9 (0.3 – 3.0)
4th Quartile (richest)	23 (34%)	11 (23%)	Ref.	20 (18%)	22 (24%)	Ref.
Disability type[1]						
Vision	6 (9%)	-	-	15 (13%)	-	-
Hearing	14 (21%)			22 (19%)		
Physical Function	53 (79%)			67 (59%)		
Intellectual Function	37 (55%)			59 (52%)		
Multiple	34 (51%)			42 (37%)		
Disability onset						
Birth	36 (55%)	-	-	57 (54%)	-	-
Under 5	9 (14%)			20 (19%)		
5-8	12 (18%)			19 (18%)		
9-12	6 (9%)			5 (5%)		
13-17	3 (5%)			5 (5%)		
Disability Severity[2]						
Moderate	24 (39%)	-	-	71 (63%)	-	-
Severe/Profound	38 (61%)			42 (37%)		

[1] Not mutually exclusive (i.e. sum >100%)

[2]Agreggate variable based on clinical and WG scores – India 5 missing values for clinical epilepsy with no severity scores, 1 in Cameroon

11.3.2 Access to education

Children with disabilities were between ten and twenty times less likely to be currently enrolled in education than children without disabilities in India and Cameroon respectively (Table 2). Almost half of the children with disabilities in the study in India (49%) and Cameroon (40%) were not currently enrolled in education, compared to 8% and 3% of children without disabilities respectively (India Odds Ratio 0.1, 95% confidence interval 0.03 – 0.2; Cameroon 0.05, 0.02 – 0.2). This equates to an attendance gap of 41% in India and 37% in Cameroon.

Amongst all children who were enrolled, children with disabilities in India were more likely both to be in a lower grade than other children their age (5.9, 1.7 – 20.5), and to have repeated at least one grade (4.1, 1.2 – 13.6). In Cameroon, children with disabilities were also more likely (2.6, 1.2 – 5.6) than children without disabilities to have repeated at least one grade, and were more likely to have taken six or more days of absence in the preceding month (10.9, 1.1 – 105.4).

Table 2: Educational Enrolment						
	India			**Cameroon**		
	Cases (n=67) N (%)	Controls (n=48) N (%)	Age and sex adjusted OR (95% CI)	Cases (n=114) N (%)	Controls (n=90) N (%)	Age and sex adjusted OR (95% CI)
Currently Enrolled						
Yes	34 (51%)	44 (92%)	0.1 (0.03 – 0.2)	68 (60%)	86 (97%)	0.05 (0.02 – 0.2)
No	33 (49%)	4 (8%)	Ref.	46 (40%)	3 (3%)	Ref.
Amongst currently enrolled children[1]						
Current Grade compared with other children same age						
Same	18 (53%)	38 (86%)	Ref.	43 (66%)	59 (74%)	Ref.
Lower	16 (47%)	6 (14%)	5.9 (1.7 – 20.5)	21 (32%)	13 (16%)	2.0 (0.9 – 4.8)
Higher	0	0	-	1 (2%)	8 (10%)	0.2 (0.02 – 1.5)
Repeated Grades						
Yes	13 (38%)	6 (14%)	4.1 (1.2 – 13.6)	45 (69%)	36 (45%)	2.6 (1.2 – 5.6)
No	21 (62%)	38 (86%)	Ref.	20 (31%)	44 (55%)	Ref.
School days missed in past month						
0 – 2	18 (53%)	21 (48%)	Ref.	35 (54%)	63 (79%)	Ref.
3 – 5	9 (26%)	19 (43%)	0.5 (0.2 – 1.7)	18 (28%)	15 (19%	2.1 (1.0 – 4.4)
6+	7 (21%)	4 (9%)	2.0 (0.4 – 10.5)	12 (18%)	2 (3%)	10.9 (1.1 – 105.4)
[1]Restricted to children currently enrolled, missing data for six controls and three cases aged 17 in Cameroon						

11.3.3 Participation amongst enrolled children

Table 3 presents item-specific experience of participation amongst children with and without disabilities currently enrolled in school. In India, children with disabilities were less likely to report that they always received support from teachers (0.2, 0.1 – 0.7), or that their friends always came to them for support (0.2, 0.1 – 0.5). Similarly, children with disabilities in Cameroon were less likely to report friends always coming to them for support (0.4, 0.2 – 0.9)

Table 3: Participation in School Activities amongst children who are enrolled[1]						
	India			Cameroon		
	Cases (n=34) N (%)	Controls (n=44) N (%)	Age and sex adjusted OR (95% CI)	Cases (n=68) N (%)	Controls (n=86) N (%)	Age and sex adjusted OR (95% CI)
Teachers are willing to help if there is a problem						
Always	23 (68%)	39 (89%)	0.2 (0.1 – 0.7)	28 (44%)	37 (45%)	0.9 (0.5 – 1.6)
Sometimes/Never	11 (32%)	5 (11%)	Baseline	35 (56%)	45 (55%)	Baseline
Friends are willing to help if there is a problem						
Always	23 (68%)	37 (84%)	0.4 (0.1 – 1.2)	19 (31%)	23 (28%)	1.1 (0.5 – 2.2)
Sometimes/Never	11 (32%)	7 (16%)	Baseline	43 (69%)	60 (72%)	Baseline
Friends come to you if they have a problem						
Always	17 (50%)	37 (84%)	0.2 (0.1 – 0.5)	11 (18%)	25 (30%)	0.4 (0.2 – 0.9)
Sometimes/Never	17 (50%)	7 (16%)	Baseline	50 (82%)	57 (70%)	Baseline
You have friends to play with at break times						
Always	27 (79%)	40 (91%)	0.4 (0.1 – 1.3)	43 (67%)	68 (80%)	0.5 (0.2 – 1.1)
Sometimes/Never	7 (21%)	4 (9%)	Baseline	21 (33%)	17 (20%)	Baseline
Your friends look up to you as a leader						
Always	9 (26%)	17 (39%)	0.6 (0.2 – 1.6)	11 (20%)	14 (19%)	1.0 (0.5 – 2.0)
Sometimes/Never	25 (74%)	27 (61%)	Baseline	44 (80%)	60 (81%)	Baseline
O**ther children hit, hurt or say nasty things to you**						
Always	12 (35%)	19 (43%)	0.6 (0.2 – 1.7)	27 (42%)	31 (36%)	1.1 (0.5 – 2.4)
Sometimes/Never	22 (65%)	25 (57%)	Baseline	38 (58%)	54 (64%)	Baseline
Teachers hit, hurt or say nasty things to you						
Always	9 (26%)	18 (41%)	0.5 (0.2 -1.3)	27 (42%)	30 (36%)	1.2 (0.6 – 2.2)
Sometimes/Never	25 (74%)	26 (59%)	Baseline	37 (58%)	53 (64%)	Baseline
You are included in lessons and activities						
Always	7 (21%)	18 (41%)	0.4 (0.1 – 1.1)	35 (55%)	45 (54%)	1.0 (0.5 – 1.8)
Sometimes/Never	27 (79%)	26 (59%)	Baseline	29 (45%)	39 (46%)	Baseline
Your school has the right materials to help you learn						
Always	15 (44%)	28 (64%)	0.4 (0.2 – 1.0)	21 (36%)	29 (37%)	0.9 (0.5 – 1.8)
Sometimes/Never	19 (56%)	16 (36%)	Baseline	38 (64%)	49 (63%)	Baseline
[1]Each item 'don't know' replaced with missing and excluded from analysis						

Mean participation restrictions were calculated across three sub-scales (inclusive school environment, peer support and experience of violence) and overall amongst cases and controls – Table 4. Cronbach's alpha of internal consistency was acceptable ($\alpha \geq 0.7$) for each sub-scale and total score in India. However, poor internal consistency was determined for each sub-scale and the total scale in Cameroon ($\alpha < 0.7$), and the latter results should be interpreted with caution.

Overall, cases faced significantly higher participation restrictions in India ($p<0.001$) but not in Cameroon. In India, after stratification, only girls with disabilities and children above the age of eight faced higher participation restrictions than controls

in the same strata. Girls with disabilities in India, and children aged 9+ also reported lower participation in terms of both an inclusive school environment and peer support (both p<0.01), but there were no differences in experience of violence. Children aged 5-8 in Cameroon faced higher restrictions than controls in the same age group (p<0.05) both overall and in terms of peer support, but due to poor α scores should be interpreted with caution.

Table 4: Participation in School Activities amongst children who are enrolled - Scales[1]

		India					Cameroon[2]				
		n	Cases ($\bar{x}$)	Controls ($\bar{x}$)	p	α	n	Cases ($\bar{x}$)	Controls ($\bar{x}$)	p	α
Total School Participation (9)[1]											
All		78	15.9	13.1	<0.001	0.77	116	15.1	14.7	0.2	0.57
Gender	Male	45	15.7	14.0	0.1		55	13.7	14.6	0.7	
	Female	33	16.2	11.5	<0.001		61	15.1	14.2	0.2	
Age Group	5 – 8	31	15.7	14.4	0.3		32	16.5	14.8	<0.05	
	9 – 12	26	16.6	12.2	<0.01		36	15.4	15.1	0.8	
	13 - 17	21	15.3	12.3	<0.01		48	14.4	14.2	0.7	
Inclusive School Environment (3)											
All		78	5.4	4.3	<0.01	0.70	131	4.7	4.7	0.99	0.48
Gender	Male	45	5.2	4.6	0.2		58	4.9	4.8	0.9	
	Female	33	5.7	3.9	<0.01		73	4.5	4.5	0.9	
Age Group	5 – 8	31	5.3	4.9	0.5		39	4.6	4.7	0.7	
	9 – 12	26	6.2	4.1	<0.01		39	4.9	4.9	0.99	
	13 - 17	21	4.8	3.8	<0.05		53	4.6	4.5	0.8	
Peer Support (4)											
All		78	6.6	5.2	<0.01	0.76	124	7.2	5.6	<0.05	0.49
Gender	Male	45	6.3	5.5	0.2		60	7.0	6.6	0.3	
	Female	33	6.9	4.8	<0.01		64	7.3	6.5	<0.05	
Age Group	5 – 8	31	6.6	5.8	0.3		33	7.6	6.3	<0.05	
	9 – 12	26	6.5	4.9	<0.05		38	7.3	6.9	0.4	
	13 - 17	21	6.7	4.8	<0.01		53	7.0	6.5	0.3	
Experience of Violence (2)											
All		78	3.9	3.5	0.3	0.78	145	3.3	3.4	0.7	0.59
Gender	Male	45	4.1	4.0	0.7		67	3.4	3.6	0.4	
	Female	33	3.6	2.9	0.1		78	3.3	3.1	0.6	
Age Group	5 – 8	31	3.9	3.8	0.9		46	3.8	3.5	0.4	
	9 – 12	26	3.9	3.2	0.2		42	3.2	3.5	0.2	
	13 - 17	21	3.9	3.7	0.7		57	3.1	3.0	0.99	

[1]Scale and sub-scale minimum scores in brackets; Higher score = higher barriers
[2]38 participants excluded from Cameroon summary scores due to 'don't know' response to one or more items

11.3.4 Barriers to enrolment

Amongst children with disabilities not enrolled in school, 88% in India (n=29) and 52% in Cameroon (n=24) had never been to school (data not shown). The child

being ill (India 42%, Cameroon 41%) and the lack of an appropriate nearby school (India 24%, Cameroon 26%) were the most common reasons reported for children with disabilities being out of school (Table 5). In addition, four children without disabilities in India and three in Cameroon were out of school, of which three had previously attended school (data not shown).

Table 5: Currently unenrolled children with disabilities and reasons not at school		
	India (n=33) N (%)	Cameroon(n=46) N (%)
Reasons child is not in school		
Cannot afford to send the child to school	4 (12%)	6 (11%)
Child lacks interest in attending school	0	6 (13%)
There is no appropriate, nearby school for the child to attend	8 (24%)	12 (26%)
The child is ill	14 (42%)	19 (41%)
The attitudes of teachers or children towards the child	1 (3%)	4 (8.7%)
Other	6 (18%)	0

11.3.5 Predictors of enrolment

Table 6 explores predictors of being enrolled amongst children with disabilities in India and Cameroon. Children with intellectual functional limitations (India: 0.2, 0.1 – 0.5; Cameroon: 0.3 (0.1 – 0.7), multiple limitations (Both: 0.2, 0.1 – 0.5) and severe/profound (as opposed to moderate) limitations (India: 0.3, 0.1 – 0.8; Cameroon 0.2, 0.1 – 0.4) were the least likely to be enrolled in both settings, as well as children with physical limitations in Cameroon (0.4, 0.2 – 0.9). Multivariate analysis adjusting for all predictors showed similar findings, but large confidence intervals eliminated the significance of all findings except severe/profound severity in Cameroon (0.2, 0.1 – 0.6) (data not shown).

Table 6: Predictors of being enrolled amongst children with disabilities						
	India			**Cameroon**		
	Currently enrolled (n=34) N (%)	Not currently enrolled (n=33) N (%)	Age & Sex Adj OR (95% CI)	Currently enrolled (n=68) N (%)	Not currently enrolled (n=46) N (%)	Age & Sex Adj OR (95% CI)
Age Group						
5-8	14 (41%)	12 (36%)	Ref.	18 (26%)	16 (35%)	Ref.
9+	20 (59%)	21 (64%)	0.8 (0.3 – 2.3)	50 (74%)	30 (65%)	1.3 (0.6 – 2.9)
Gender						

Male	18 (53%)	18 (55%)	Ref.	29 (43%)	27 (59%)	Ref.
Female	16 (47%)	15 (45%)	1.1 (0.4 – 2.8)	39 (57%)	19 (41%)	1.8 (0.8 – 4.8)
Household SES						
Poorest Half	18 (53%)	19 (58%)	Ref.	41 (60%)	34 (74%)	Ref.
Richest Half	16 (47%)	14 (14%)	1.2 (0.5 – 3.1)	27 (40%)	12 (26%)	1.8 (0.8 – 3.7)
Disability measure[1]						
Vision	3 (9%)	3 (9%)	0.9 (0.2 – 5.2)	11 (16%)	4 (9%)	1.9 (0.5 – 7.3)
Hearing	8 (24%)	6 (18%)	1.3 (0.5 – 3.6)	12 (18%)	10 (22%)	0.7 (0.3 – 2.0)
Physical Function	25 (74%)	28 (85%)	0.5 (0.2 – 1.6)	34 (50%)	33 (72%)	0.4 (0.2 – 0.9)
Intellectual Function	13 (38%)	24 (73%)	0.2 (0.1 – 0.5)	28 (41%)	31 (67%)	0.3 (0.1 – 0.7)
Multiple	11 (32%)	23 (70%)	0.2 (0.1 – 0.5)	16 (24%)	26 (57%)	0.2 (0.1 – 0.5)
Disability onset						
Birth	17 (50%)	19 (59%)	Ref.	35 (56%)	22 (50%)	Ref.
Beyond Birth	17 (50%)	13 (41%)	1.6 (0.7 – 3.9)	27 (44%)	22 (50%)	0.8 (0.4 – 1.6)
Disability Severity[2]						
Moderate	16 (52%)	8 (25%)	Ref.	53 (79%)	18 (39%)	Ref.
Severe/Profound	15 (48%)	23 (74%)	0.3 (0.1 – 0.8)	14 (21%)	28 (61%)	0.2 (0.1 – 0.4)

[1]Non mutually exclusive binary variables

[2]Agreggate var based on clinical and WG scores – India 5 missing values for clinical Epilepsy cases with no severity scores, 1 in Cameroon

11.3.6 Water, Sanitation and Hygiene

In India, of the 34 children with disabilities enrolled in school, one could not use the same sanitation facilities, drinking source or water source for hand-washing as other children, whilst two others could also not use the same sanitation facility. Similarly, in Cameroon of the 68 children attending school, one child did not use the same sanitation facility as children without disabilities, and two used a different water source for hand-washing.

11.4 Discussion

Compared with almost universal enrolment amongst children without disabilities in the study, half of the children with disabilities in India and 40% in Cameroon were not attending school, meaning that they were between ten and twenty times less likely to be enrolled than age, sex and community matched peers without disabilities. Amongst children with disabilities who were not enrolled in school,

88% in India and 52% in Cameroon had never attended. Commonly reported barriers included the child being unwell, and the lack of an appropriate, nearby school in both settings.

Our study substantiates the limited number of robust quantitative studies globally that have reported continued exclusion from education amongst children with disabilities. Kuper et al. (2014) and Filmer (2008), reported widespread exclusion of children with disabilities from school in LMICs. The attendance gap between children with and without disabilities in this study (41% in India and 37% in Cameroon) was similar to that found in a secondary analysis by Mizunoya et al. of 18 nationally-representative surveys in 15 LMICs which estimated an average attendance gap of 30.2%, quantifying the concept of children with disabilities being "*left behind*" [51, 52, 227].

In both India and Cameroon, children with intellectual limitations, multiple limitations, and more severe limitations were less likely to be enrolled in school than other children with disabilities, whilst children with physical disabilities were also less likely to be enrolled in Cameroon. Our findings align with Kuper et al. (2014) who similarly found both higher likelihood of exclusion amongst children with communication or physical limitations, and no association with gender [51, 232]. Moreover, our findings identify common barriers to education amongst children with disabilities out of school – the child's health and a lack of appropriate school nearby. Whilst the peer-reviewed literature is limited, evidence from grey literature suggests stigmatised cultural expectations as promulgated in the attitudes of parents, teachers or other students, the physical accessibility of the educational environment, the availability of inclusive learning resources and teachers adequately trained in inclusive methods, and the child's health intersect to create barriers to education [42]. This is an area in urgent need of further research, particularly qualitative research that unpacks the perspectives of the child, the caregiver and the teacher in ensuring access to quality education.

Our findings also highlight lower attainment and quality of educational experience amongst the minority of children with disabilities that do attend school, compared

to children without disabilities. Children with disabilities who were enrolled in school were more likely to have repeated a grade in both settings, more likely to be in a lower grade than their peers in India and reported greater participation restrictions than children without disabilities. These included a lack of teacher support, inclusion in lessons and appropriate materials, although due to small cell sizes findings were not significant in Cameroon. Few studies from LMICs are available to compare our findings. However, a recent study by Devries et al. (2014) also reported lower educational outcomes for children with disabilities compared to children without disabilities in Uganda, as well as higher physical and sexual school-based violence [233].

Overall, the findings from this study confirm an unacceptable disparity between global legislation mandating the right to quality education for all children, and the continued exclusion of children with disabilities in these two settings that urgently needs addressing. Lack of access to education perpetuates the cycle of disability and poverty by limiting post-school opportunities for children with disabilities [67]. Further, it denies them the broad-reaching, empirically proven additional benefits of education, including better health outcomes, lower risk of violence, greater gender equality, higher social capital and awareness of rights [234]. Prevalence estimates obtained by the wider study within which this research was situated suggest that the prevalence of child disability (ages 0-17) is 4.7% in Cameroon and 3.6% in India, whilst other studies suggest that the proportion of children with disabilities in LMICs may be increasing inversely to declining under-five mortality rates and increasing neo-natal services [44, 206]. There is therefore an urgent need to appropriately plan and resource policies and programmes that guarantee access to quality education for children with disabilities in LMICs.

In 2010, Miles and Singal critiqued the parallelism of the Education for All (EFA) and Inclusive Education movements, for continuing to segregate polices, practitioners and programmes related to the education of children with disabilities from mainstream education frameworks and funding streams. They, and a number of other scholars, warned that such a separation of activities decreased both the focus on, and integration of, children with disabilities, thereby reinforcing policy gaps

contradicting human rights legislation [226, 235, 236]. Moreover, given the lack of clarity on policy, there is also little evidence of effective strategies for quality inclusion of children with disabilities in education globally, but particularly in LMICs. A recent review by Bakhshi et al. (2013), for example, was unable to identify any evidence from the peer-reviewed literature of a rigorous evaluation of approaches to increase access to education amongst children with disabilities in LMICs [237].

In 2015, the Education for All movement launched the Education 2030 Framework. Yet whilst the rhetoric of the framework is dominated by "*inclusion*" and "*equity*", specific reference to the mechanisms, finances, physical and human resources needed to ensure that children with disabilities are fully supported in accessing quality education remain scant [224]. Thematically, Wapling (2016) breaks down approaches to quality education of children with disabilities as external (i.e policy, legislation, pedagogy or funding), teacher-focused, child-focused, school-focused, mixed-focus and parent/community-focused [226]. This includes a wide-ranging set of programmes and activities from teacher-training and curriculum overhaul; to peer-support; the accessibility of physical infrastructure, materials and transport; and community awareness-raising to de-stigmatise perceptions of disability. Whilst the grey literature in particular refers to the specifics of these approaches in practice, systematic application or rigorous assessment of the effectiveness or relative impact of each on the goal of quality education for children with disabilities, is almost entirely absent [226, 237, 238]. As such, policy frameworks are rendered ineffectual – or more critically, "*symbolic*" – by a dearth of evidence-based recommendations, limiting efficient resource allocation and scale up of services [239]. There is an urgent need to address this gap to ensure equal opportunities for children with disabilities.

Given that the majority of out-of-school children with disabilities in the current study had never previously been enrolled, the role of Early Childhood Care and Education is also crucial to identify children with, or at risk of, disability from an early age. Children with disabilities require sufficient support in accessing quality education both in relation to the removal of barriers (e.g. parental attitude or poor

health) and provision of facilitators (e.g. ensuring that local facilities and educators have the requisite skills and resources to provide an enabling environment). Moreover, our findings highlight ill health as a core barrier to education, which must also be addressed. A multi-sector community-based Early Childhood Care and Education model that effectively coordinates between child health, wellbeing and educational mechanisms is recommended by Engle et al. 2016, together with the need to evaluate the relative impact of different programmes [240].

Our findings determine important disparities in access to education between children with different types and severity of limitation. Authors such as Urwick and Elliot (2010) have cautioned against the "*orthodox demand*" for inclusive education without evidence on the effectiveness of inclusive approaches for all children with disabilities [235]. It is generally agreed that the modification of physical infrastructure or adaptation of learning materials for children with mild, moderate or specific types of impairments (such as physical impairments) will help provide them with a quality inclusive education. However, evidence is lacking on whether the needs of children with more complex additional needs are adequately met in current inclusive education practices and given available resources.[235] It is imperative that indicators of access to "*quality education for all*" include determinants of attainment and participation, but also disaggregation by disability type or severity, to ensure that the needs of all children with disabilities are met in a non-tokenistic way.

One commonly reported barrier in the literature, to monitoring and evaluating the effective inclusion of children with disabilities in education (and to disaggregating amongst children with disabilities), is the perceived difficulty in defining disability across different cultures and settings [45, 236]. However, recent developments such as the release of the UNICEF/ Washington Group Survey Module on Child Functioning provide a simple, caregiver-reported tool for the identification of children at risk of disabilities age 2 and above[231]. Advocacy for quality inclusion in education for children with disabilities should include the incorporation of this tool into national population-based surveys and Census activities, to provide

country-specific disability disaggregated school enrolment data and ensure access to quality education for all.

11.4.1 Strengths and Limitations

We undertook a large population based case-control study in two settings to determine attributes of educational enrolment for children with and without disabilities. Our approach to measuring disability was comprehensive, and our findings contribute to a small evidence base on the subject. In terms of limitations, we did not undertake conditional regression analyses due to imperfect matching between children with and without disabilities. The small number of children with disabilities enrolled in school led to low power in analyses of participation restrictions in school.

11.5 Conclusion

Our study shows that children with disabilities in India and Cameroon are substantially less likely to be in school than children without disabilities, whilst the minority who are enrolled achieve lower grades and face higher participation restrictions. Whilst the rhetoric of inclusion is common in international educational legislation, there is a scarcity of evidence on effective, scalable approaches to quality education for children with disabilities which must be addressed as an urgent priority by the international education community.

11.6 Declaration of interests

This study was funded by CBM International. The funder did not have any role in study design, collection, analysis or interpretation of the data, writing the manuscript or the decision to submit the article for publication.

Chapter Twelve: Discussion

12.1 Summary of findings

Collection of disability data is essential so as to monitor both the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and progress towards an inclusive Sustainable Development Agenda. Both are required to ensure meaningful inclusion of persons with disabilities in their societies, on an equal basis with others.

To support this endeavour, this study aimed to develop a comprehensive population-based survey methodology of disability, and to explore the inter-relationship between tools measuring different components of disability in two population-based surveys. Secondly, the study used this methodology to assess i) the prevalence of disability and ii) the lived experience of disability, including predictors of inclusion amongst persons with disabilities.

12.1.1 Review of tools

Chapter Three reviewed tools related to different components of disability developed for, or used in, population-based surveys of disability in Low and Middle Income countries. The review was separated into sub-sections on 1) tools to objectively measure impairments in body function or structure, 2) tools to measure reported functional limitations and 3) tools to measure reported participation restrictions.

A variety of tools were identified in each sub-section. Tools developed to objectively measure impairments in body function or structure were generally well-validated, but many incorporated lengthy, resource-intensive examination protocols [100, 101, 103, 109]. Rapid Assessment tools for MSI and vision were identified and incorporated into the survey protocol [77, 96], alongside a simplified version of the WHO Ear and Hearing Disorder Survey Protocol[78]. The Patient Health Questionnaire was selected for clinical depression screening in adults given its prior validation in both survey settings[121, 122]. No appropriate tools for the objective measurement of intellectual functioning in population-based surveys were

identified. All impairment tools included in the study provided clear criteria for determining thresholds of impairment from mild to severe or profound.

Several eligible tools were identified for the measurement of reported functional limitations in population-based surveys. Of these, two were prohibitively lengthy [123, 147] and several did not contain items on core domains of functioning, such as sensory domains [124] or domains related to mental function[141]. Few tools reported a threshold for estimating disability prevalence in population-based surveys [46, 141, 147]. The majority of tools [72, 130, 136, 147, 149] had undergone either qualitative or quantitative validation testing. Based on the review, the Washington Group Extended Set on Functioning for Adults, and the UNICEF/Washington Group Draft Module on Child Functioning were selected to provide the best compromise between feasibility and comprehensitivity for inclusion in the population-based surveys [142, 241].

Domains of participation restriction were included in several of the afore-mentioned reported functional limitation tools [25, 125, 136, 242]. Several participation-specific tools were identified via a recent systematic, scoping review by Seekins et al. (2012), but few of these had been used in more than one study and the authors did not report either whether they had been used in population-based surveys or whether they had been used in LMICs[153]. A tool by Van Brakel et al. (2006) was also identified which had been field-tested in three LMICs in populations with specific health conditions [157]. The most widely-used tool was the participation module included in the Surveys of Living Conditions amongst People with Activity Limitations in Developing Countries, which was therefore included in the nested case-control component of the study[158].

12.1.2 Development of a comprehensive population-based survey methodology

Based on the review of tools, a population-based disability survey methodology was developed (Chapter Four). This included an all-age population-based survey (n=4080) in two settings (Fundong Health District, North West Cameroon and Mahahbugnagar District, Telangana State, India), with nested case-control study.

Participants were selected for inclusion in the survey via randomised cluster sampling, with probability proportionate to size. All participants in the population-based survey were a) screened for visual, hearing and musculoskeletal impairments, epilepsy and (aged 18+) depression using clinical tools and b) interviewed for self-reported functional limitations (age 2+), as described in section 1.2.1.1 above. Participants were included in the disability prevalence estimate if they were identified to have a moderate or worse impairment, experienced epilepsy or clinical depression, or reported 'a lot' or greater difficulty (significant functional limitations) in the following functional domains: Children 2-17: seeing, hearing, walking self-care, understanding, being understood, learning, remembering; Adults 18+ years: seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self-care, upper body strength, fine motor dexterity.

All participants aged ≥5 years who either self-reported significant functional limitations, or were identified to have epilepsy, depression or a moderate or worse impairment were invited to participate in a nested case-control study. For each case, one community, age and sex matched control not meeting case criteria was also selected. Additional case-finding was undertaken, aiming to identify one additional adult and two additional children with disabilities per cluster, to ensure adequate sample size for the nested case-control component of the study.

Cases and controls undertook a structured interview incorporating modules on socio-demographics, socio-economic status, livelihoods, education, health, water and sanitation, activities and participation. An additional module for cases only recorded perceived cause and history of disability and access to and awareness of rehabilitation services, assistive devices and rights.

Data were collected in one district each of Cameroon (Fundong Health District, North West Region, 2013) and India (Mahabubnagar District, Telangana State, 2014).

Data using the UNICEF/Washington Group Draft Module on Functioning for Children collected during the population-based surveys was used to further refine the module (Chapter Five).

12.1.3 Prevalence of disability, impairments and functional limitations

Chapter Six presents the overall prevalence of disability, using the prevalence estimate thresholds described in Section 13.1.2 above. The overall population prevalence of disability was 10.5% in Cameroon (C) and 12.2% in India (I). The prevalence of significant reported functional limitations ('self-reported cases') was 5.9% and 7.5% respectively, compared to 8.4% and 10.5% prevalence of moderate or worse impairments/health conditions ('clinical cases'). In both countries and across tools used, the prevalence was similar in women and men and increased substantially with age.

In both countries, the most commonly reported significant functional limitations among children (aged 2–17) were in walking, remembering and learning (walking C:0.8%, I: 0.8%; remembering C: 1.1%, I: 0.8%; learning C: 0.6%, I: 0.9%). Amongst adults (18+), difficulties in walking/ climbing, seeing and hearing were most commonly reported (walking/climbing C: 5.5%, I: 4.8%; seeing C: 3.0%, I: 3.6%; hearing C: 2.0%, I: 3.7%). Hearing impairment was the most prevalent moderate/worse impairment in both countries (C: 3.6%; I: 4.4%), followed by MSI (C: 3.4%; I: 3.5%), and visual impairment (C: 2.3% I: 3.5%).

Additional prevalence data for all levels of reported functional limitation and impairment (including those below the threshold for inclusion in the disability prevalence estimate) are reported in Chapter Seven. As expected, reported functional limitations at the level of 'some' or greater difficulty were substantially higher than at the level of 'a lot' or greater (C: 58.3%, I: 47.0%). This included 20.1% of children 2-17 in Cameroon and 11.4% in India reported to have at least 'some' difficulty learning, and almost half of adults in Cameroon (46.4%) and over one third in India (38.0%) reported at least 'some' difficulty walking/climbing.

Mild clinical impairments were also more prevalent than moderate or worse impairments in each setting, and were higher in the oldest age group (50+) across impairment types. Including mild impairments, MSI was the most prevalent (C: 11.6%, I: 19.6%) followed by similar prevalence of all levels of vision (I:8.9%) and hearing impairment (C: 8.1%, I: 8.8%).

12.1.4 The relationship between measures of objectively-measured clinical impairment and self-reported functional limitations

Of participants meeting the criteria for inclusion in the disability prevalence estimate, one third (33%) in Cameroon and almost half (45%) in India, were both self-reported and impairment cases (Chapter Six). A smaller proportion (C:21%, I:14%) were self-reported cases only. Of these, 41% and 74% respectively were identified to have mild clinical impairments, whilst 68% and 84% (not mutually exclusive) reported significant functional limitations in domains not directly screened clinically (e.g. remembering, concentrating). The remaining 47% and 41% of participants meeting the criteria for inclusion in the disability prevalence estimate in Cameroon and India respectively were clinical cases but not self-reported cases. Of these, the vast majority (93% of adults in both settings, 69% of children in Cameroon and 53% of children in India) reported at least 'some' functional limitation, but no domains with 'a lot' or greater difficulty.

Comparison of reported participation restrictions between i)self-reported only cases, ii) self-reported and clinical cases and iii) clinical only cases showed no differences amongst child participants. Amongst adults, reported participation restrictions were highest ($p<0.01$) for those in category ii) compared with categories i) and iii).

Chapter Eight explored the relationship between specific clinical impairments (MSI, VI, HI) and related self-reported functional limitation domains (walking/climbing, seeing, hearing). For the purpose of comparison, the impairment was considered the gold standard and the self-reported domain as the test. Specificity – i.e. the proportion of participants without clinical impairments reporting no difficulties in

the corresponding domain – was high (76 – 100%) across all three pairs, using either broad or restricted categories of both self-report and impairment severity. Sensitivity – i.e. those with clinical impairments reporting functional limitations in the corresponding domain – was highest when comparing moderate/worse impairment to reporting at least 'some' difficulty across each of the three pairs (62 – 84%). Sensitivity decreased when comparing moderate/worse impairment to reporting at least 'a lot' of difficulty across the three pairs (21 – 62%).

However whilst Negative Predictive Value at this threshold (the proportion of those reporting no difficulties who did not have a moderate/worse impairment) was high across pairs (85 – 100%), Positive Predictive Value (the proportion of those reporting 'some' or greater difficulty that had moderate/severe impairments in the corresponding domain) was very low (9 – 18% across all pairs with the exception of 62% for hearing in India). This suggests that self-reported functional limitation tools and clinical impairment tools may be identifying different sub-populations.

The low PPV may be a function of persons with moderate or worse impairments not perceiving these as limiting their function. For example, through accommodating their limitations in vision or hearing via assistive devices, or acceptance of musculoskeletal impairment without perceiving this as causing substantial difficulties walking or climbing. It may also exemplify discordance between the classification of impairments in comparison with functional limitations. A moderate hearing impairment, for example, may not lead to perceived difficulties in hearing despite the defined impairment threshold.

12.1.5 The lived experience of disability and contextual predictors of associations

Chapters Nine to Eleven present data on the associations between disability and major life areas, from the nested case-control study component of the research.

Socio-demographic and socio-economic characteristics of Case-Control participants

A total of 937 cases and 611 controls were enrolled into the nested case-control study across the two sites. In Cameroon, 331 of the 429 enrolled cases were identified via the population-based survey, with an additional 98 identified via additional case finding. In India, of 508 cases, 402 were identified via the survey and 106 from case finding. The number of controls (274 in Cameroon and 337 in India) is lower than cases in both settings due to the high prevalence of disability in older adults. This limited the number of available control households in each cluster as we did not select controls from the same households as cases.

Physical limitations accounted for the highest proportion of disability in adults in both samples (55% of cases in India and 60% in Cameroon), followed by sensory limitations (vision 39%, hearing 40% in India, vision 34%, hearing 38% in Cameroon. Physical limitations were both the most prevalent limitation identified in the population-based sample, and may have been over-represented in the additional case-finding for the case-control survey compared to less visible limitations. Amongst adults with disabilities, reported age of onset was lower in Cameroon (15% within the first five year of life) than India (41%). 76% of persons with disabilities enrolled in the study in Cameroon, and 56% in India, experienced moderate functional limitations, with the remainder in each setting experiencing severe or profound functional limitation.

Amongst adults, there were no differences between people with and without disabilities in terms of prior education or literacy, rates of which were low for adults with and without disabilities in both settings. Adults with and without disabilities were well matched on gender, but adults with disabilities were more likely to be in the oldest age group (C:OR=2.9, 95% CI 1.9 – 4.4; I:5.3, 3.2 – 8.9) due to incomplete matching. Adults with disabilities were between three and a half times (3.6, 1.6 – 8.3) and twice as likely (2.6, 1.3 – 5.3) never to have married compared to adults without disabilities in Cameroon and India respectively. There were no differences

in socio-economic status in Cameroon, but adults with disabilities were more likely to be in the poorest socio-economic quartile in India (1.6, 1.1 – 2.4).

Children with and without disabilities were well-matched by age group and sex in both settings, and there were no observed differences in household socio-economic status. In both Cameroon and India, the highest proportion of children with disabilities had physical functional limitations (Cameroon 59% of children with disabilities, India 79%) whilst over half (Cameroon 52%, India 55%) experienced intellectual limitations. Over half of children with disabilities in each setting (Cameroon 54%, India 55%) reported that they had acquired their limitations at birth, with proportions generally diminishing with age. Approximately one third of children with disabilities in Cameroon (37%) and two thirds in India (61%) experienced severe or profound limitations.

Health and rehabilitation (Chapter Nine)

Persons with disabilities (adults and children) were twice as likely in Cameroon (1.9, 1.4 – 2.7) and three times more likely (3.2, 2.1 – 4.8) in India to report experiencing a serious health problem in the previous twelve months, compared to people without disabilities, increasing with age group. Seeking health care for serious illness was high amongst both people with and without disabilities in both settings, and cost was the most commonly reported barrier to health amongst persons with disabilities who did not seek health care (reported by 77% in Cameroon and 94% in India).

Coverage of assistive devices (proportion using the device amongst those reporting needing the device) was high for walking sticks and person-guides in both Cameroon (93%, 67%) and India (87%, 86%) However, despite high expressed need for both glasses and hearing aids, coverage was low in both settings (C:33%, 24%; I: 46%, 6%). In both settings, persons with disabilities expressed a low awareness of, need for and receipt of rehabilitative services. Amongst those few who reported needing specific rehabilitation services however, coverage was relatively high.

Livelihoods (Chapter Ten)

Adults with disabilities in both settings were five times less likely (C:0.3, 0.2 – 0.5; I: 0.2, 0.2 – 0.4) to be working compared to adults without disabilities. This relationship held across age groups, gender, marital status, and education level. The employment gap between adults with and without disabilities was 21% in Cameroon and 34% in India. Amongst adults who were working, there were no differences in the type of work undertaken by adults with and without disabilities in either setting, however adults with disabilities in India were more likely to undertake irregular, rather than regular, work (2.0, 1.3 – 3.1).

Among adults with disabilities in both settings, key predictors of working were younger age, being married and not having a physical limitation. However even in the oldest age group of 65 and above, adults with disabilities were substantially less likely to be working than people without disabilities. In addition, likelihood of working was positively associated with prior education in Cameroon (2.0, 1.1 - 3.6), and negatively associated with being female (0.5, 03 – 0.7) or in the highest socio-economic quartile (0.4, 0.2 – 0.8) in India.

Adults with disabilities more commonly reported their age, and their health or disability as the main barriers to working, whilst adults without disabilities most frequently reported undertaking unpaid activities (such as housework) and their age.

Education (Chapter Eleven)

Almost half of the children with disabilities in the study (C: 40%, I: 49%) were not currently enrolled in education, compared to 3% and 8% of children without disabilities respectively (C: 0.05, 0.02 – 0.2; I: 0.1, 0.03 – 0.2). This equates to an attendance gap of 37% in Cameroon and 41% in India. Amongst children with disabilities who were not enrolled in school, 52% in Cameroon and 88% in India had never attended. Commonly reported barriers included the child being unwell, and the lack of an appropriate, nearby school in both settings.

Children with disabilities who were attending school were more likely to have repeated at least one grade than other children their age in both settings (C: 2.6, 1.2 – 5.6; I: 4.1, 1.2 – 13.6). In terms of participation, children with disabilities were less likely to report that their friends turned to them for support (C: 0.4, 0.2 – 0.9; I: 0.2, 0.1 – 0.5), and in India less likely to report support from teachers (0.2, 0.1 – 0.7).

In India, children with disabilities reported higher participation restrictions overall ($p<0.001$). After stratification, girl with disabilities and children above the age of 8 ($p<0.001$, $p<0.01$) reported higher participation restrictions than peers without disabilities. Aggregated scores for school-based participation restrictions did not meet adequate internal consistency criteria in Cameroon (Cronbach's alpha ≥0.7).

Children with intellectual functional limitations (C:0.3, 0.1 – 0.7; I: 0.2, 0.1 – 0.5), multiple limitations (both: 0.2, 0.1 – 0.5) and severe/profound limitations (C:0.2, 0.1 – 0.4; I: 0.3 – 0.1 – 0.8) were least likely to be enrolled in both settings.

12.2 Implications of findings

12.2.1 Measuring disability in population-based surveys

The ICF framework provides a comprehensive, but complex, definition of disability that has led to the development of different methodologies to measure disability in population-based surveys. Whilst some methodologies focus on reported functional limitations, others include objective screening of impairments and some, but not all, incorporate reported participation restrictions. Even within the broader scope of self-reported methodologies, different tools contain items on different ICF domains. By virtue of this heterogeneity, many available data sources are non-comparable, capturing different sub-populations and components of the ICF in different ways.

The Relationship between Reported functional limitations and impairment screening

The use of tools to objectively measure clinical impairments described in the UNCRPD definition of disability (namely long-term physical, mental, intellectual or sensory impairments) was explored, alongside tools to measure self-reported functional limitations, in two population-based surveys. For comparison, direct question on whether the participant considered themselves to have a disability, was included in India.

The substantial lack of overlap between the sub-populations identified by the clinical and self-report tools, and the single question, has several major implications.

First, the study confirms the incompatibility of the use of direct questioning in population-based surveys harmonious with the ICF. The population prevalence using the single question was far lower in India than that identified via the clinical or self-report tools. Consequently, in concurrence with other similar findings, this approach to measuring disability should be avoided in surveys[68].

Secondly, the study confirms that tools to objectively measure impairment in isolation are insufficient in measuring disability compliant with the ICF. This is argued conceptually through the ICF framework, which mandates a broader measurement of functioning than purely at the level of body function and structure, [20]. This point is also confirmed through the findings from the study. Specifically, 21% of participants identified to have a disability in Cameroon and 14% in India were identified via self-report only, and would be missed by the impairment tools included in this study, showing that these do not identify all participants with functional limitations. Furthermore, the unavailability of appropriate clinical screening tools for mental function (broadly including intellectual functioning, psychosocial functioning, emotion, energy and drive in the ICF) prevents comprehensive measurement of impairments in population-based surveys, especially in low and middle income settings.

Thirdly, 46% of those considered to have a disability in Cameroon and 41% in India were identified via clinical impairment tools only, and did not report a significant functional limitation in the respective self-reported domain. Specifically, participants with moderate impairments or impairments in vision or hearing, were less likely to self-report functional limitations at the level of 'a lot' or greater difficulty. In theory this supports the argument that persons with significant impairments do not necessarily experience significant functional limitations in their lived context. However, the sub-population identified to have moderate or worse impairments but did not report significant functional limitations reported significant participation restrictions compared to controls. This suggests that self-reported functional limitation tools in isolation may also under-estimate disability as defined in the ICF. This gap emphasises that self-report tools are missing many people with moderate/worse impairments who are at risk of participation restrictions. Further – ideally qualitative – research is needed in this area, to assess whether this discrepancy is related to the distinction between impairments and functional limitations as theorised in the ICF, or whether this identifies caveats in the interpretation and response to reported functional limitation tools. This research is important for furthering our understanding of both the process of disability and functioning in the ICF, and approaches to disability measurement compatible with this. In addition, collecting impairment data offers the opportunity to identify health and rehabilitation interventions that maximise functioning, providing important information for informing developing health and rehabilitation services and so is arguably a valuable addition to surveys.

The findings suggest that – where feasible – tools to measure functional limitations could be combined with tools to objectively measure clinical impairments in population-based surveys of disability. This allows a comprehensive measurement of disability compatible with the ICF. One approach, where resources allow, would be to utilise a self- reported functional limitation tool followed by clinical screening of all those who report 'some difficulty' in functioning in relevant domains. This would identify 94% of persons with disabilities in Cameroon and 95% in India, based on the study criteria. Such an approach would allow data to be collected and compared using the internationally agreed and comparable standard (self-report)

whilst also ensuring adequate information on impairments and identifying a broader population at risk of participation restrictions. In addition, surveys using self-reported tools only, should be aware of the potential under-estimation of significant impairment related to participation restriction this may lead to.

The choice of threshold in determining disability prevalence using self-reported functional limitation tools

As described in Chapter Three, at the time of data collection neither of the self-reported functional limitation tools used in the study (The WG ESF and draft UNICEF/WG ESF) reported pre-validated thresholds for determining the prevalence of disability either by reported severity of limitation, or in terms of domains to include. Further, the UNICEF/WG ESF was still under development at the time of data collection.

Therefore, the choice of threshold and domains to include in the prevalence estimate was based on available literature for the WG SSF and direct communication with the tools' developers. The threshold was agreed as reporting 'a lot' or greater difficulty in any one of the following domains: Children 2 – 17: seeing, hearing, walking, self-care, communicating, learning, remembering; Adults 18+: seeing, hearing, mobility, communicating, remembering or concentrating, self-care, upper body strength, fine motor dexterity.

Retaining the domains included in the initial prevalence estimate, but widening the threshold to include 'some difficulty' increased the population prevalence to approximately 50% of the all-age population. Further analysis comparing specific clinical impairments to the relevant reported functional domain determined highest sensitivity, and reasonably high specificity, between reporting 'some' or greater difficulty and being identified to have a moderate or worse clinical impairment in the same domain. However, at this threshold, the Negative Predictive Value ranged from 9 – 18%, suggesting that the classification of 'some' may be problematic. One reason could be that it is interpreted in different ways by respondents. Whilst this may in part be related to appropriate translation, it also raises questions of

interpretation and warrants further research. Consequently, this research supports the WG recommendation to include only participants reporting 'alot' of difficulty or worse in disability prevalence estimates derived from self-reported functional limitation[72].

We did not include self-reported functional domains related to affect (i.e. symptoms of anxiety or depression as recorded in the ESF) in the overall disability prevalence estimate or analysis in Paper Two, given that these items were under development at the time of data collection. However, prevalence of Level 1 (highest) depression and anxiety presented in Chapter Seven based on recent guidance on analysis by the WG, were high in both settings [145]. Since this research was undertaken, recent recommendations on analysis of the ESF from the Washington Group include the classification as used in this study, in addition to Level 1 depression and anxiety indicators[145]. Given the well-established participation restrictions experienced by people with mental health disorders, the inclusion of these domains in prevalence estimates using the WG ESF are important to ensure comprehensive measurement of disability in population-based surveys [243].

Additional advantages of incorporating objective clinical impairment tools

It would not be appropriate to recommend the inclusion of clinical impairment tools in census data collection methodologies, given the inherent resource needs of such an exercise. However, as argued above, combining tools that measure self-reported functional limitations and objectively determined clinical impairments in population-based surveys of disability can provide a more comprehensive understanding of disability than either approach in isolation. This approach has a number of additional advantages, particularly in the context of unmet health and rehabilitation needs of people with disabilities.

Objective clinical impairment tools used in this study allowed the estimation of both cause of impairment and health and rehabilitation referral requirements (see Appendix 1 for impairment manuscripts). Persons with disabilities in this study were shown to experience more frequent episodes of ill-health in both settings than

persons without disabilities, and to report their health as a barrier to both livelihoods and education. These findings, which have also been shown elsewhere, highlight the direct relationship between health and participation restrictions within the overall lived experience of disability, and the need to prioritise the health needs of persons with disabilities. Universal Health Coverage is a core component of the Sustainable Development Agenda (Goal 3.2), defined by the universal ability of individuals to obtain the health services they need without experiencing financial hardship to do so [33, 244, 245]. In this context, the collection of impairment data is important.

Impairment, health and rehabilitation data can be used to identify interventions to maximise functioning of people with impairments, as one mechanism to positively influence the lived experience of disability. It should be clarified that this recommendation does not subscribe to a 'medical model' understanding of disability, but challenges the rhetoric that clinical interventions – specifically when combined with non-clinical interventions – are non-compatible with supporting inclusion of persons with disabilities in their societies as per the ICF and UNCRPD. For example, consider two adults, both reporting 'a lot' of difficulty seeing. The data on their reported functioning can be used to assess disability prevalence, or disaggregate data by disability. Using a clinical tool in addition to a reported functional limitation tool, it is possible to determine that one adult has developed dense cataract, which can be surgically corrected at low cost to improve his or her vision substantially. This simple procedure can maximise functioning and minimise participation restrictions. The other has non-correctable vision loss caused, for example, by glaucoma. Appropriate mechanisms to support inclusion for this participant may include provision of assistive devices to support independence and economic productivity. In either example, mechanisms to diminish participation restrictions at the societal level are imperative, but the direct support to the individual's functioning differs in relation to the cause of their underlying impairment. I therefore argue that population-data on impairments, combined with data on functional limitations and participation restrictions, supports a bio-psycho-social approach to supporting the full inclusion of people in their societies to achieve their full potential on an equal basis with others.

Availablility of high cadre clinical specialists is frequently low in low-resourced settings[246]. For example, the regional ratio of eye surgeons (ophthalmologists and cataract surgeons) in Sub Saharan Africa to the general population is 2.9 per million population[247]. The ethics of including highly-skilled clinicians in population-based surveys, is therefore questionable given the population need. The involvement of mid-level clinicians as opposed to specialists in this study increases the feasibility of collecting impairment data without burdening the health system. In addition, recent innovations in mobile tools for impairment screening – such as the development of the Portable Eye Examination Kit and HearTest – further open opportunities for lower cadres of healthcare professionals to undertake clinical screens [248, 249]. Such tools – which have been validated against relevant gold-standard clinical screens – can be deployed on mobile devices by trained non-clinical personnel. This would reduce the need for full-time clinical team members, with specialists only needed to visit participants failing the screen criteria to provide any diagnosis or referral as appropriate.

A priori versus a posteriori estimation of disability prevalence thresholds

A key distinction between the tools developed by the Washington Group (WG) used in this study, and tools developed by the World Health Organisation (WHO) to measure disability in population-based surveys is the use of *a priori* versus *a posteriori* classification of thresholds. Both the WG tools and the recently developed WHO Model Disability Survey (MDS) broadly incorporate self-reported functional limitations across a range of ICF domains. However, unlike the WG, the MDS does not support the determination of a threshold or cut off in advance. Instead, disability prevalence is determined statistically, based on the complete distribution of participant responses following data collection [126]. The relative merits of these two approaches have been debated between the two groups [126, 250, 251].

The *a posteriori* classification of disability based on response distribution in the MDS may provide a more comprehensive description of the continuum of functioning

across a given population and the contextual factors in that population's respective environment. However, by definition, this approach prevents field methodologies from classifying participants as having a disability prior to, or during, data collection. If the aim of the data collection exercise is to ascertain the continuum of functioning of the population, and the statistical competency of the data collectors is of sufficient expertise, the MDS provides a comprehensive methodology to this end. In contrast, if the aim of the data collection activity is to estimate the population prevalence and lived experience of disability, an *a priori* approach that allows field classifications may be more practical. Applying a 'case' definition of disability *a priori* allows a population-based survey methodology to incorporate a nested case-control approach as used in this research, allowing comparison between people with and without disabilities and providing essential data on inclusion and exclusion. An *a posteriori* classification of disability would require the collection of data related to the lived experience on all participants prior to their classification. This may not be feasible given the time burden of collecting such in-depth data, and may adversely affect the quantity of surveys undertaken.

The selection of tools used within the study across the components of the ICF

A scoping literature review was undertaken as part of this research, to review ICF-compatible tools for the measurement of disability in population-based surveys (Research Study Objective 1). The review set out to separate tools by the three levels of dysfunctioning as categorised by the ICF; i.e. tools to measure 1) impairments in body function or structure, 2) activity limitations and 3) participation restrictions. However, this proved unfeasible due to both the way that most tools had been designed across these components, and to a lack of clarity in the ICF itself on disaggregating these components. The tools included were selected based on their prior use, validation and applicability, but could not be clearly categorised by ICF component as initially planned.

Participation restrictions – defined in the ICF as problems an individual may experience in involvement in life situations – were measured in two ways in this study [18]. First, a specific participation restrictions module, developed by SINTEF,

was incorporated into the case-control study[159]. Secondly, individual modules in the case-control study on access to health, education, livelihoods and WASH provided in-depth data on participation restrictions related to these key life areas. Both approaches provided important data on this component of the ICF, and the inter-relationship between participation restrictions, impairments and reported functional limitations. The study results showed that participants both self-reporting functional limitations and identified to have moderate/worse clinical impairments reported the highest participation-restrictions, but that participants who had only either self-reported functional limitations or moderate/worse impairments, still experienced higher restrictions than controls. This implies that those who self-report functional limitations in combination with identified moderate/worse impairments experience the highest level of participation restrictions, compared to those who either self-report only, or who are identified to have a clinical impairment only.

A limitation of this study was the assessment of participation restriction within the case-control study only rather than for all participants in the population survey. To further understanding of the relationship between impairment and reported functional limitation data on participation restriction could be recorded for all participants in population-based surveys.

Field-Testing of the draft UNICEF/WG ESF in the study

As noted, the UNICEF/WG ESF was still under development at the time of data collection. The final module was launched in October 2016 and is available in Appendix Six. The final module comprises two versions - one for ages 2 to 4 and one for ages 5 to 17. Items in the version for 2-4 years olds are similar overall to the version used in this study, although the domain of fine motor function has been added. Similarly, items in the version for 5-17 year olds measure the same domains used in this study, although the hearing domain question has been reworded and additional questions related to walking long and short distances, and being understood in and outside the household, have been added based on final testing of the draft module[241].

UNICEF and the Washington Group recommend that an adult proxy-respondent should be used to record data on child functioning using the UNICEF/Washington Group ESF[72, 150]. However, a number of studies have questioned the validity of proxy report of child health or health-related quality of life. Specifically, proxy response related to observable dimensions (such as physical health or wellbeing) have tended to show high correlation with child self-response, whilst proxy response to less observable dimensions (such as those related to social or emotional function) has been shown in a number of studies to be less reliable [252, 253]. For this reason, children aged 9 and above in the present study self-reported on functional limitations unless unable to communicate directly.

A similar proportion of children in Cameroon and India were reported to have 'a lot' or greater difficulty with one or more functional domain, but there were large differences between the proportion reported to have 'some' or more difficulty in at least one domain in Cameroon (64%) and India (35%)[128]. This may further suggest variation in the conceptualisation of 'some' difficulty generally and the broad spectrum of 'normal' child development this may encompass. With age stratification, the greatest difference in reporting 'some' or more difficulty in at least one domain was in the 9-12 age group, who were the youngest age group to self-report, adding to the debate on the appropriate age for self-report. Older children (who self-reported) reported significantly greater difficulties seeing in both settings, and more difficulties hearing and remembering in India, compared to younger children whose caregivers reported on their behalf[128]. Given previously reported evidence of the limitations of parental proxy-report of sensory limitations in children, this may suggest false negatives when parental report is used compared with child self-report [46].

Data disaggregation by disability in the SDGs

The findings of this study support the inclusion of impairment data in population-based surveys of disability for the reasons outlined above, adding to significant ongoing debate in this area. However, I recognise the importance of the collection of

comparable data on disability for data disaggregation in SDG indicator monitoring. To maximise the potential for comparable data collection, a simple, quick and resource un-intensive tool is necessary, that can be easily accommodated in generic data collection (e.g. census, health information systems). For this purpose, I support recent calls by the United Nations Statistical Commission and representatives of disabled persons' organisations to use the WG-SS.

Groups excluded from the population-based survey methodology developed for this study

Infants below the age of 2 years

The lack of availability of tools to accurately measure disability in infants in population-based surveys is an area of ongoing debate[45, 254]. Clinical impairment tools included in this study for vision, hearing, MSI and epilepsy incorporate methods for assessing infants, but the tool included for measuring functional limitations (UNICEF/WG ES-F) does not. This exclusion was decided by the developers of the UNICEF/WG ES-F, given that the potential for false-positives in children below two years of age was prohibitively high, due to the diversity of development in the first two years of life that may not constitute long term functional limitations[45].

Using the UNICEF/WG ES-F, children in the youngest age range (2-4) were the least likely to have reported difficulties of any level in any domain in both settings ($p<0.001$). Given the low prevalence in younger children and the complexities related to estimating risk of disability across a broad spectrum of development in this age group, one suggestion may therefore be to continue not to include infants in disability prevalence estimates established via population-based surveys. Instead, a separate focus could be on infant assessment for functional limitation in all primary care settings. This approach, with a focus on surveillance –for example training primary health workers to ask opportunistic and flexible questions related to the child's development at each interaction with the health service – is recommended by authors such as Yousafzi et al (2014)[240]. Tools such as the Ages

and Stages Questionnaire and Denver II are particularly recommended for the identification of developmental delay, but require careful validation to ensure cultural appropriateness [255, 256]. Moreover, aggregation of surveillance data to provide population estimates is already utilised in multiple areas of public health, including to estimate the prevalence of autism spectrum disorders in children below the age of three in the United States [257, 258]. Such an approach might provide population estimates with greater rigour and validity than attempting to capture reported functional limitations amongst infants in population-based surveys.

Persons with mental function limitations

The lack of validated clinical screens for mental function screening across age groups prevented a fully comprehensive exploration of tools in this research to measure this component of disability. This is a critical limitation in the field of disability measurement currently, particularly in a survey setting, and is considered a priority by leading scholars in global mental health [64, 74, 259, 260]. Specifically, the lack of research on cultural validation of tools to measure either common mental disorders or intellectual functioning prevents survey methodologies from adequately capturing this population in LMICs.

It is essential therefore, that items related to mental functioning in self-reported function tools capture this domain in a meaningful way. As a member of the Washington Group Mental Health Working Group, this research has prompted further development of affect items within the Washington Group tools, and a systematic review of self-reported mental function items is underway. This is a crucial area of continued research, so as to be able to appropriately and accurately identify persons with mental function limitations in population-based surveys of disability.

Institutionalised, homeless and transient populations

A generic limitation of population-based surveys is the exclusion of institutionalised, homeless and transient populations from the sample [261]. A

review of the prevalence of disability in the incarcerated population in the United States estimated it to be between two and three times higher than the population-based prevalence, and particularly high in relation to mental function limitation[262]. The same study estimated that all elderly residents of nursing homes experienced disability. A separate study in Addis Ababa, Ethiopia, suggested that persons with disabilities comprised a disproportionate proportion of beggars in the city, due to lack of familial and societal support for persons with disabilities in the country[263]. Such disproportionate prevalence of disability in groups excluded from population-based survey methodologies means that these surveys may underestimate the true prevalence, and requires further research. In particular, the potential causality between disability and institutionalisation or homelessness warrants the development of appropriate mechanisms that document this disparity and seek to overcome it. Without this, the overall objective of meaningful inclusion of persons with disabilities in their societies cannot be achieved.

Comprehensivness of the survey design

As outlined in this section, there are a number of caveats that arguably prevent the survey methodology developed in this research from being truly comprehensive. These include the lack of available tools to identify disability in infants, the exclusion of institutionalised, homeless and transient populations, and the limited availability of tools to assess mental health function beyond clinical depression measures. Further, through only collecting data on participation restrictions within the case-control study, the methodology provides incomplete data on this component of the ICF at the population level. The aim of this research study was to develop a "comprehensive population-based survey methodology for disability". Rather, the findings of this study suggest a way forward in terms of the collection of data across different components of disability. It is not, however, a fully comprehensive survey methodology, and should not be promoted as such given the limitations outlined above.

12.2.2 Defining disability and its components – ongoing challenges

This study highlights the continued diversity of interpretation of both the World Health Organisation (WHO)'s ICF and the UNCRPD definition of disability, and the impact this has on measurement approaches and ultimately disability data.

The ICF defines disability as an umbrella term, encompassing dysfunctioning at one or more of three interlinked levels (impairments, activity limitations and participation restrictions) as the result of the interaction between a health condition and contextual factors. Similarly, the UNCRPD describes disability as "*an evolving concept that [...] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*"[31].

The first challenge is therefore related to the overall definition of disability itself, which is considered to be evolving in the UNCRPD and a process in the ICF. Given this, there is a certain artifice in labelling a person as having a disability or not, with the temporal and situational element of disablement not captured by cross-sectional data. For the purposes of disability measurement in population-based surveys, this limitation is acceptable, but a clearer theoretical justification is warranted in key texts related to the ICF.

The second challenge is related to the lack of clarity on the role of impairment within the overall definition of disability in the ICF. As previously noted, impairment is not considered an appropriate proxy for disability in the ICF. This understanding has diminished the support for objective measurement of impairment, given that this does not reflect the individual's functioning in his or her environment. There are several caveats as a result of this exclusion. Firstly, as discussed above, this curtails collection of data that are essential to plan and implement inclusive health and rehabilitative services for persons with disabilities. Such services are necessary to support maximising an individual's functioning both at the level of their own body and functions, and – with health highlighted as a major reported barrier to education/livelihoods – at the level of their participation in society[264].

Secondly, this raises confusion in the closely related sphere of disability assessment. Whilst not the focus of this work, transparent assessment of disability is necessary in a number of situations, such as determination of eligibility criteria for social protection or other support mechanisms that seek to support the meaningful inclusion of persons with disabilities in their societies[265]. Recent high-level meetings at the WHO consider the process of providing recommendations on disability assessment as altogether separate to recommendations on disability measurement in population-based surveys (personal communication). Draft guidance on disability assessment from the WHO states that the first step in the disability assessment process is "*an assessment to estimate the extent of impairment(s) that a claimant has and how such impairment(s), in interaction with the specific context of the person concerned, triggers barriers to participation*" [266]. A fundamental component of disability assessment is therefore measurement of impairment, whilst this is considered inappropriate in other WHO activities related to population-based data.

Therefore, challenges and debate about disability measurement are unsurprising given lack of uniformity in understanding of the ICF. A uniform understanding is needed, particularly for the purposes of disability measurement in population-based surveys. This hypothesised uniform approach ought to incorporate measures of impairments, activity limitations and participation restrictions in combination, for the multiple arguments raised above. Distinction is needed within the ICF and those using this framework (such as the UNCRPD) on the relative merit of capturing objective data on functioning, and how this can be used in addition to self-reported tools.

Beyond the impairment/disability debate, Babulal et al. (2015) lament the "*myriad of problems*" created by the inclusion of participation restrictions as a health outcome in the ICF, without sufficient "*historical premise, philosophical description, or theoretical grounding to validate linkages between the two concepts*" and operationalise clear methodological guidance[267]. The authors perceive participation as a non-delimited term, overlapping in concept with wellbeing and

quality of life. A second critique is the exclusion of participation satisfaction (i.e. how satisfied the individual is with their level of participation across various domains) from ICF terminology. The UNCRPD statement refers to "*meaningful*" inclusion, but current tools developed for capturing the prevalence of disability do not incorporate a measure of satisfaction with participation or quality of life. Incorporation of satisfaction within the ICF may support a more comprehensive understanding of participation restrictions and the meaningful inclusion of persons with disabilities.

In summary, there is a need for further reflection on, and clarification of, the ICF. Impairment, as a necessary but not sufficient component of disability, must be highlighted and acknowledged in ICF documentation. The relationship between the three core levels of the ICF – impairments at the level of the body, limitations at the level of the person and restrictions at the level of society – require a more thorough theoretical definition. This is necessary for the interpretation of data collection across different components of the ICF.

Secondly, there is a particular need to overcome unclear delimitations of "participation" within the ICF framework. As outlined above, this is problematic thematically, further limiting interpretation of data and consequently the utility of such data. These revisions are necessary, to ensure that data collected to support the full inclusion of persons with disabilities in their societies is effective.

12.2.3 Implications of Disability Prevalence in Cameroon and India

Using the threshold of significant self-reported functional limitation or moderate or worse impairment to determine disability prevalence, this study estimated the prevalence of disability to be just over one in ten of the all-age population in both study settings. It is difficult to compare this estimate with other studies, given the well-explored forewarning of different methodologies deployed in other data collection activities. Available data from the 2011 Demographic and Health Survey in Cameroon estimated an all-age prevalence of disability of 5.4%[172]. This study used a measure of self-reported functioning only, which is similar to the prevalence

of self-reported functional limitation identified in our study in Cameroon (8.4%). The 2011 India Census estimated a prevalence of 2.2% using a single question disability screen. Again, this is similar to the estimate in this study derived from the single question (3.8%), suggesting that these findings are comparable to studies using similar approaches. Moreover, the similarity of findings across both settings in our study reflects a consistency and standardisation of the methods used.

Disability was shown to increase exponentially with age, from less than 5% of children below the age of eighteen, to over one third of adults aged fifty and above, in both samples. This finding is well established, yet important for several reasons[2]. First, it shows that disability is common across the lifespan, and therefore the need for all mainstream policies and programmes to acknowledge and accommodate the population with disabilities in their design and implementation. Secondly, particularly with respect to the older population, the findings necessitate a paradigm shift towards acknowledgement of functional limitations over the life course. Diminishing function with age is a generally accepted, and in many societies is not considered within the overall framework of disability. For example, the WHO World Report on Ageing and Health 2015 describes a framework for "*ageing and health*" that references functioning, but not disability[268].

12.2.4 The lived experience of disability in Cameroon and India

Substantial restrictions to major life activities were observed across both datasets in terms of access to and experience of health and rehabilitative services, education, livelihoods, participation and WASH amongst children and adults with disabilities. Adults with disabilities were also less likely to be married in both settings, and adults with disabilities were more likely to be in the poorest socio-economic quartile in India.

These results provide much needed empirical data on the lived experience of disability in these settings, and the exclusions experienced by persons with disabilities of all ages from their societies. These data identify the personal and

contextual factors that influence the lived experience of disability, which can be used to identify and overcome barriers to meaningful inclusion. In addition, they provide a crucial baseline to monitor both implementation of the UNCRPD, and programmes within the Sustainable Development Agenda. The implications of the findings related to health and rehabilitation, livelihoods and education are explored in depth in the relevant chapters. In addition, the key impliations are reiterated here.

Health and Rehabilitation

Persons with disabilities may experience ill health as a consequence of their underlying impairment, or because an under lying condition (such as diabetes) causes both ill health and impairment. In addition, ageing and poverty are also independently related to both disability and poor health. Moreover, poor health was identified as a key barrier to both education and livelihoods for persons with disabilities in the study.

Consistent with other recent studies in India and Sierra Leone, we did not identify differences in health-seeking behaviour between people with and without disabilities in the study [269, 270]. Whilst this is surprising given reported barriers to accessing health in other studies, a potential explanation of this pattern may be the relative proximity to services in both study settings [245, 254, 271]. These districts were purposefully selected due to the availability of health services in each locality for onward referral of survey participants determined to have unmet health and rehabilitative needs, which may not be representative of the country. For example, in Cameroon a large faith-based hospital in the region assisted in the provision of free services, and in India the health worker density in the region was considerably larger than the country-wide average[272]. Secondly, equality of access does not necessarily mean equality of experience, which requires more nuanced questioning than included in our study. Similarly, the association between health and barriers to education and livelihoods reported in the study warrants further investigation on the quality of health services received, and action to demonstrate whether health service provision provides adequate support to persons with disabilities and is adequately inclusive in scope[273].

In addition, there was clear evidence that persons with disabilities had low awareness of rehabilitation services, and consequently were not often using these services. This finding supports the aim of the WHO's Global Disability Action Plan to increase access to rehabilitation services, as well as health services, among persons with disabilities[274]. A central implication of this study is therefore that awareness and availability of rehabilitation services needs to be increased in both India and Cameroon. Further work is needed to ensure health information is accessible at the community level and to provide clear networks for rehabilitative referral through appropriate policy design[59].

Livelihoods

The prevailing literature on participation in livelihood activities amongst adults with disabilities in LMICs is relatively limited, but corroborates the substantial restrictions to livelihoods identified in this study [140, 207, 211]. As explored in Chapter 10, this provides evidence of the theorized pathway from disability to poverty, via restrictions on economic independence, and is contrary to the UNCRPD[31]. Whilst labour market analyses in HICs provide data on barriers to work, studies in LMICs – where livelihood activities are often more complex – are lacking. These data are important to develop appropriate mechanisms to support adults with disabilities in gaining meaningful livelihoods on an equal basis as others, as mandated by the UNCRPD.

Adults with disabilities who were unmarried or experienced physical functioning limitations were the least likely to be working in both settings. In addition, women with disabilities in India were twice as likely not to be working as men with disabilities. This exposes the heterogeneity of the lived experience of disability, and in the latter instance highlights the "*double discrimination*" experienced by women with disabilities [212, 213]. Appropriate mechanisms to support meaningful livelihoods must take such heterogeneity into account, and accordingly data collection efforts must ensure adequate disaggregation within the overall population considered to have a disability so as to meet diverse needs.

Education

As elucidated in Chapter 11, the wide gap between enrolment rates of children with and without disabilities in both settings is similar to estimates of exclusion from education reported by a small number of other published studies in LMICs [51, 52]. Considering almost universal enrolment of children without disabilities in both settings, this observed education gap quantifies the concept that non-inclusive development progress results in children with disabilities being "*left behind*"[227].

These findings provide further evidence on the theorized pathway between disability and poverty, through the denial of the right to education for children with disabilities and the limit this imposes on their future livelihood opportunities and wellbeing [67, 234]. Moreover, given that the majority of children with disabilities out of school in both sites had never been to school, this further strengthens the call for early childhood surveillance by primary health workers. This is crucial so as to identify children with, or at risk of, disability from an early age and ensure the appropriate support mechanism are established to provide them with a quality education [240].

Common barriers to education reported in both settings included the child's health and the lack of an appropriate school nearby. Moreover, amongst children with disabilities, children with intellectual limitations, multiple limitations and severe (as opposed to moderate) limitations were the least likely to be enrolled in both Cameroon and India. Again, this highlights the heterogeneity of the lived experience of disability and requires inclusive policies and programmes to consider and be reflexive towards diverse support needs.

12.3 Study Strengths and Limitations

The study provides in-depth ICF-compatible data on the population prevalence of disability in two settings, using a combination of tools to measure reported functional limitations and observed impairments. Robust epidemiological methods

were utilised to minimise sampling bias and maximise representativeness of the study findings. In addition, the nested case-control component of the study provides rich data on associations between disability and major life areas, and on predictors of access amongst persons with disabilities.

Based on the outcomes of the review of tools undertaken to meet objective one of this study, a number of methodological limitations were identified. Firstly, validated and appropriate tools to objectively measure mental function were not available in the literature, likely excluding some participants with mental function limitations from the survey estimates. This limitation was compounded by the exclusion of affect domains from the reported functioning estimate generated using the WG ESF.

Secondly, the review found a lack of pre-validated, robust tools for reported functional limitation in children, and consequently a draft tool (UNICEF/WG ESF) was included that had not yet undergone extensive testing or formal validation.

Thirdly, this tool excluded infants below the age of two, meaning functioning data on this population were not collected. Fourthly, at the time of the surveys neither of the included reported functioning tools (the WG/ESF and the UNICEF/WG ESF) specified thresholds for estimating disability prevalence in population-based surveys. As discussed in section 12.2.1, these thresholds have since been established and whilst similar, do not directly match those used in this study which may limit comparability to future studies.

Fifthly, Epilepsy was included as a potentially disabling health condition, but other health conditions with potentially disabling functional outcomes such as HIV or diabetes were excluded. The assessment of all health conditions in this study would not have been feasible. Given that seizures represent a specific functional phenomenon that is not captured in either the Washington Group questions or the clinical impairment tools used in the study, it was included specifically. However, this addition may limit the comparability of our findings to ogther disability surveys, Further exploration is needed in future studies as to whether or not epilepsy should be included in overall estimates, or perhaps presented separately.

The second objective of this research was to develop a comprehensive population-based disability survey methodology, and to undertake this survey in one district each of two countries. Within each survey, a nested case-control study was included to estimate the associations between disability and major life areas. In terms of the survey, the use of proxy respondents to respond both for younger children and for older children/adults unable to communicate directly may have introduced some reporting bias. The verbal translation of tools into local languages may have further introduced reporting bias, although considerable time was spent on translation and training to minimise this impact. From an epidemiological perspective, the situation of data collection sites close to available health services, may have meant higher access to health care amongst the sample when compared to other districts or states in each country setting. Whilst this method was important for ethical reasons, it may have decreased the generalisability of the study findings beyond the district in which it was conducted. Finally, the exclusion of institutionalised, homeless and transient populations is a generic limitation of population-based surveys but may be particularly problematic given the relationships between disability and each of these situations.

In regards to the case-control study methodology, the process of additional case-finding is likely to have identified individuals with more 'obvious' and severe disabilities, and potentially leading to under-representation of participants with more hidden impairments such as cognitive or hearing limitations or depression. In addition, due to the high prevalence of disability in older adults, the number of eligible controls was lower than the number of cases, meaning that matched analysis could not be completed. Stratified analysis as included in the results was therefore important to overcome this limitation. A broad limitation of the use of case-control data to estimate associations between disability and major life areas is the inherent cross-sectional nature of the data, limiting inferences on causality.

Specific limitations in the case control data analysis included the use of a relatively narrow 'working' variable for the livelihoods analysis in Chapter Ten rather than more comprehensive assessment of livelihood. In Chapter Eleven, the high proportion of children with disabilities out of school limited the power of analyses

related to school participation. Across chapters Nine, Ten and Eleven, the SES principal component analysis (PCA) variable constructed was limited to assets only, and may not have adequately captured SES, accounted for limited associations found between disability and SES.

12.4 Conclusion

This study adds to the considerable ongoing debate related to appropriate measures for population-based disability measurement within the ICF. Disability is an umbrella concept and this study highlights that measurement at the level of impairments, activity limitations or participation restrictions will identify different samples. There is a need for the theoretical construction of the ICF to be revised, highlighting the relationships between the different components of the framework. In addition, the concept of participation restrictions is in need of theoretical clarification to support collection and interpretation of data against this component.

The study findings provide clear evidence of the continued exclusion of persons with disabilities in both study settings from education and livelihoods, as well as highlighting the additional health needs of persons with disabilities. They further contribute data on the lived experience of disability, as well as documentation of the barriers to inclusion and suggested solutions.

Finally, this study provides a suggested way forward for the measurement of disability in population-based surveys that would support the meaningful inclusion of persons with disabilities in their societies; alongside evidence on the lived experience of disability in one district each of Cameroon and India.

Appendix 1: Impairment Papers

Appendix One includes three additional manuscripts documenting further impairment data from the Cameroon study. These papers include analyses on impairment cause, previous treatment and onward referral for specific impairments (vision, hearing and MSI) identified in the study. These are included in the Appendix as they are beyond the scope of the present thesis, but are shown here to provide further evidence of the added value – where feasible – of collecting impairment data in population-based surveys of disability. Note that manuscripts on impairments India have not yet been finalised, so are not included in the present work.

1A: Prevalence and causes of visual impairment in Fundong District, North West Cameroon: Results of a population based survey

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Journal of Ophthalmic Epidemiology
Please list the paper's authors in the intended authorship order:	Joseph Oye, Islay Mactaggart, Sarah Polack, Elena Schmidt, Violet Tamo, Marvice Okwen, 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)	Coordinated data collection, prepared data for analysis, conducted analyses, provided edits and critical feedback on manuscript

Student Signature: [redacted] Date: 30.03.2017

Supervisor Signature: [redacted] Date: 30.03.2017

Prevalence and causes of visual impairment in Fundong District, North West Cameroon: Results of a population based survey

Running head: Blindness in Cameroon

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This paper has not been published anywhere previously and is not simultaneously being considered for any other publication. It was submitted for publication to British Journal of Ophthalmology, but was not accepted because their restricted word count did not allow sufficient details to be described of the study.

ABSTRACT

Purpose: To estimate the prevalence and causes of visual impairment in Fundong Health District, North West Cameroon.

Methods: Fifty-one clusters of 80 people (all ages) were sampled with probability proportionate to size and compact segment sampling. Visual acuity (VA) was measured with a tumbling "E" chart. An ophthalmic nurse examined people with VA<6/18 in either eye. The presence of hearing and physical impairments were assessed using clinical examination, and self-reported visual problems using the Washington Group Short Set.

Results: In total, 4,080 people were enumerated of whom 3,567 were screened (response rate 87%). The overall prevalence of visual impairment was 2.3% (95% CI=1.8-3.0%) and blindness was 0.6% (0.3-1.0%). The prevalence of both blindness and visual impairment increased rapidly with age, so that the vast majority of cases of visual impairment (84%) and blindness (82%) were in people aged 50+. Posterior segment disease and cataract were the main causes of blindness and visual impairment, with refractive error also an important cause of visual impairment. Cataract surgical coverage (proportion of all cataracts that had received surgery) was relatively high (87% of people at VA<6/60). Post-surgery outcomes were poor, with 31% of operated eyes having VA<6/60. Among the 82 people with visual impairment, 22% had a physical impairment or epilepsy and 30% had a hearing impairment. Self-reported difficulties in vision were relatively closely related to clinical measures of visual impairment.

Conclusions: Ophthalmic programmes in Cameroon need to incorporate control of posterior segment diseases while also working to improve outcomes after cataract surgery.

INTRODUCTION

Globally there are an estimated 191-285 million people living with visual impairment (VI), of whom 32-39 million are blind. [1, 2] Over 80% of cases of VI are either treatable (e.g. cataract) or preventable (e.g. trachoma), and around 85% of people with VI live in low and middle income countries (LMICs).[2] Estimates of the prevalence of VI in people aged 50 years and above are relatively robust, due to the widespread use of the Rapid Assessment of Avoidable Blindness (RAAB), as RAAB focuses on this age group,[3] and to date at least 266 RAABs have been conducted globally.[4] However, fewer surveys are available that include younger people, and consequently much less is known about the prevalence and causes of VI across all age groups.

There are also other knowledge gaps with respect to surveys of visual loss. Older people are vulnerable to VI, but also to other types of impairment (e.g. hearing, physical).[5] However, few surveys consider multiple types of impairment and so have not assessed how these conditions overlap. This is an important gap, as the presence of other impairments may make it more difficult for people to access vision-related services and also for clinicians to communicate effectively with people about their eye care needs. Consequently, a focus on inclusive eye health services may be needed, as is already promoted by some organizations.[6]

Furthermore, self-reported data on difficulties with vision are widely available because they are relatively easy to collect and form a core component of disability measures. As an example, the Washington Group Short Set questionnaire, which are promoted by the UN and other groups for the collection of disability statistics, ask

about whether the person surveyed experiences difficulties in seeing.[7] Routine collection of this information therefore potentially provides a large pool of data on the prevalence of sight difficulties. However, few studies have assessed the validity of these self-reported measures compared to clinical tools for visual impairment assessment.[8, 9]

In response to these evidence gaps, we conducted an all-age population-based survey of VI in Fundong Health District, North West Cameroon. The purpose of the study was three-fold: (i) to estimate the prevalence and causes of VI (all ages); (ii) to estimate the prevalence of other types of functional difficulties in people affected by VI; and iii) to measure sensitivity and specificity of visual screening using the Washington Group Short Set tool compared to clinical visual acuity assessment.

MATERIALS AND METHODS

Study design

A population-based cross sectional survey was conducted during August-October 2013 in Fundong Health District, North West Cameroon. This district is predominantly rural. All selected participants underwent clinical examination and completed an interviewer-administered questionnaire. A detailed description of the study design has been published. [10, 11]

Sampling

The expected prevalence of VI was conservatively estimated at 4%.[2] The required sample was therefore 4,056, assuming precision of 20% around the estimate, 95% confidence, a design effect of 1.5 and 20% non-response.

Fifty-one clusters of 80 people were selected using probably proportionate to size sampling with the 2005 census data as the sampling frame. Within clusters, households were selected using compact segment sampling.[12] For this sampling method, maps of the cluster were divided into segments of approximately 80 people and one segment was randomly selected. The enumerators visited all households door-to-door in that segment until 80 people (all ages) were enumerated.

Household members were informed about the survey and invited to attend an examination clinic at a central location over the next two days. If an enumerated resident did not attend the clinic the enumerators visited their household at least

twice to encourage attendance. The survey team visited all participants at home who were unable to travel to the clinic.

Screening for visual impairment

All participants attending the clinic were screened for VI. For participants aged >5 years, visual acuity (VA) was assessed using a tumbling 'E' chart with 6/18 size optotype on one side and 6/60 on the other. Pinhole vision was assessed if vision was VA <6/18 in either eye. Vision was categorised according to the presenting vision in the better eye as:

- Blind: VA<3/60
- Severely visually impaired: VA<6/60 but >=3/60
- Moderately visually impaired: VA<6/18 but >=6/60
- Normal vision: VA>=6/18
- VI: VA<6/18

For children aged under 2 years, vision was assessed by ophthalmic nurses using the fix and follow method. For children aged 2-4 years counting fingers was used whereby the child was asked to count or copy the number of fingers held up by the nurse/assistant standing at 6 meters. Children who failed these tests were counted as having a VI (VA<6/18), but severity was not assessed.

All people with presenting VA<6/18 had their eyes examined by an ophthalmic nurse using a direct ophthalmoscope to determine the likely cause of vision loss.

These participants were also asked about whether they had undergone cataract surgery and reasons for not attending cataract surgery, where relevant.

Screening for other impairments

Participants were also assessed for the presence of other impairments at the examination camp.

Hearing: All participants were screened through an otoacoustic emissions (OAE) hearing test (validated as a tool for screening for hearing loss) [13]. Participants who failed this test in both ears or for whom a reading could not be taken underwent Pure Tone Audiometry screening to assess the level of hearing impairment. Hearing in each ear was measured at 1KHz, 2 KHz, 4 KHz, 0.5KHz and again at 1KHz to ensure consistency of response and the average reading for each ear across the 4 frequencies was recorded. Children <4 years underwent OAE testing only. People were classified as having a "Moderate or greater" hearing impairment if they had an average hearing level of >41db (adults aged >18 years) or >35db (children 4-18 years). The level of hearing impairment was not classified in children below the age of 4.

Physical impairment and epilepsy: Participants were asked six screening questions to assess the presence of: a) difficulty using the musculoskeletal system b) use of mobility aid c) whether the participant considers any body part to be misshapen and d) whether they have experienced seizures.[14] Any participant answering "yes" to at least one question was examined by a physiotherapist or orthopaedic clinical officer

to determine the presence of a moderate/severe physical impairment and/or epilepsy.

Measuring self-reported difficulties

Self-reported difficulties in vision were assessed using the question from the Washington Group on "Do you have difficulty seeing, even if wearing glasses? ", with possible answers given as "no difficulty", "some difficulty", "a lot of difficulty" and "cannot do at all".[7] In addition, people were asked if they had difficulty in hearing, walking/climbing steps, remembering/concentrating, washing/dressing or communicating. People were classified as having a disability if they reported "a lot of difficulty" or more in at least one domain.

Fieldworker training

Three survey teams each consisting of 1 ophthalmic nurse, 1 ear nose and throat (ENT) nurse, 1 physiotherapist or orthopaedic clinical officer, 2 enumerators, 3 field assistants and 2 interviewers received 10 days training. The inter-observer variation for the measurement of vision, hearing and physical impairment level and diagnosis of cause was assessed against a gold standard (ophthalmologist, ENT surgeon and orthopaedic surgeon, respectively) to ensure it was of an acceptable standard (i.e. Kappa ≥0.6). The survey protocol was pilot tested for suitability.

Data analysis

Data were analysed using STATA version 14. Prevalence estimates and 95% confidence intervals were generated for vision impairment, disaggregated by severity, age and gender. The svy command was used to derive prevalence estimates accounting for the cluster sampling design. Sensitivity, specificity, predictive values positive and negative were estimated comparing clinical measures to self-reported difficulties with seeing. First, using a broader definition of vision loss (i.e. "some" or more difficulty seeing reported) and then using a more restrictive definition of vision loss (i.e. "a lot" or more difficulty seeing).

Ethics

Ethical Approval for the study was obtained from: the London School of Hygiene & Tropical Medicine (UK), the National Ethics Committee for Research in Human Health (Cameroon) and the Cameroon Baptist Convention Health Board Institutional Review Board (Cameroon). We adhered to the guidelines of the Declaration of Helsinki during the conduct of the study. All participants who attended the screening gave written/finger print informed consent. For people aged <21 years a caregiver was required to provide consent and remain present throughout the screening. All participants with unmet health needs were referred to relevant services.

RESULTS

In total, 4,080 people (51 clusters of 80 people) were enumerated for the survey, of whom 3,567 were screened (response rate 87%). The age distribution of the study participants was generally similar to the census estimates, although females were overrepresented in the sample (Table 1). Among the non-responders, only 0.5% (n=17) refused to participate, whilst the remaining 12.7% (n=521) were unavailable at the time of the study. Mean age was higher amongst non-attenders (28.5 95% CI 26.8-30.1 years) than those examined (24.4 years 95% CI 23.6-25.1). Gender distribution was similar between those examined (59% female) and non-attenders (56%), but refusers were more likely to be female (65%).

The overall prevalence of VI (VA<6/18) was 2.3% (95% CI=1.8-3.0%) and the prevalence of blindness (VA<3/60) was 0.6 (0.3-1.0%) (Table 2). The prevalence of both blindness and VI increased rapidly with age, so that the vast majority of cases of VI (84%) and blindness (82%) were in people aged 50+. The prevalence of VI was similar in males (2.5%, 1.7-3.8%) and females (2.2%, 1.6-3.0%), while blindness was more common in males (0.9%, 0.5-1.8%) than females (0.3%, 0.2-0.9%).

The main cause of blindness and VI were both posterior segment disease followed by cataract (Table 3). Posterior segment disease included diabetic retinopathy, glaucoma, ARMD, in the absence of cataract, refractive error or other anterior segment causes. Refractive error was a leading cause of visual impairment, but not of blindness. Only 0.3% of people in the survey wore glasses for refractive error correction. Among the 8 children (age<18) with VI, the leading cause was posterior

segment disease (75%) followed by refractive error (25%). Posterior segment disease was also the most common cause of VI for adults aged 18-50 years (67%) followed by cataract (33%). Among the 66 adults aged >50 with VI, 35% was due to cataract, 33% to posterior segment disease, and 22% to refractive error. In terms of blindness in this age group, 60% was due to posterior segment disease, while cataract was responsible for 27%. Causes of blindness and VI were therefore similar among people aged >50 years to in the total population.

Fifty-two eyes had been operated for cataract, among people identified in the survey, and the mean time since operation was 6.6 years (SD=6.9).The cataract surgical coverage (CSC – i.e. proportion of all cataract patients or eyes that have received cataract surgery) was relatively high (87% of people and 61% of eyes at VA<6/60). CSC for people was lower in males (83%) than females (91%). Nearly a third of eyes (31%) had a poor outcome after surgery (VA<6/60), which improved slightly after correction for refractive error (27%). Cause of poor/borderline outcome was available for 23 out of 29 eyes with VA<6/18 after cataract surgery. Ocular co-morbidity (35%) and refractive error (35%) were the leading causes of poor/borderline outcome. Long-term complications (i.e. where there was initially a good outcome, with subsequent vision loss apparently due to postoperative capsule opacification or retinal detachment) was responsible for 26% of poor/borderline outcomes, while operative complications were rarely the cause (4%). Almost all people (97%) had undergone surgery at Mission hospitals. The most common reported barriers to cataract surgery among those with VI<6/18 due to cataract, were inability to afford surgery (59%), lack of perceived need for surgery (33%) and lack of awareness that treatment was possible (30%).

Among the 82 people with VI, 22% (95% CI: 14-32%) had a physical impairment or epilepsy and 30% (22-41%) had a hearing impairment. Among the 17 people who were blind 18% (6-41%) had a physical impairment or epilepsy and 41%(22-64%) had a hearing impairment. Furthermore, almost half (49%, 95% CI: 38-59%) of people with VI had "a lot" or more difficulties in at least one domain other than vision, as assessed by the Washington Group Short Set. People with other functional difficulties (excluding those due to vision problems) had lower CSC than those without functional difficulties (83% vs 92%), although this difference was not statistically significant (p=0.09).

Self-reported difficulties in vision were closely related to clinical measures of VI (Table 4). Of the 82 people with VI, 65 reported "some" or more difficulties with seeing (sensitivity=79%) and 25 reported "a lot of difficulty" or more with seeing (sensitivity = 30%). Of the 3229 people who had no VI (VA>=6/18), 2582 reported no problem with seeing (specificity = 80%). Of the 2599 who reported that they had no problem with seeing, 2582 also had no VI (negative predictive value of 99%). Among 712 people who said that they had "some" or more problem with vision, 65 had VI (positive predictive value of 9%). However, if this was restricted to the group reporting "a lot of difficulty" or more then the positive predictive value increased to 46%.

DISCUSSION

This study conducted in Fundong district in North-West Cameroon had a number of findings that are important from both the programmatic and methodological perspective in order to address the needs of people affected by VI in Fundong district and other similar contexts.

The all age prevalence of blindness in this study (0.6%) was similar to the estimates for Africa from the WHO global review (0.7%), while the prevalence of VI (2.3%) was lower than in the review (3.3%).[2] Two previous surveys were conducted in Cameroon, both among people aged 40+ years. When restricting our estimates to people aged 40+, the prevalence of blindness (2.0%, 1.2-3.3%) and vision impairment (8.4%, 6.3-10.9%) reported in this study were similar to those from the rural area (1.6% and 10.2%)[15] but higher than in the urban area (1.1% and 4.4%).[16] As expected from the global review,[2] the prevalence of VI and blindness increased rapidly with age, with the majority of VI cases found in people aged 50 years+, even though this group only constituted 18% of the survey sample. Furthermore, the causes of VI in this age group were reflective of the causes across the whole population. These findings provide strong rationale for the continued use of RAAB which focuses on people aged 50+, as the prevalence of VI is highest in this age group so that a smaller sample size is required for surveys, yet the causes of VI reflect those of the population of all ages, allowing planning of public health strategies. These results therefore tally with those previously made using data from the Gambia, which also supported the use of surveys in people aged 50+ for assessing visual impairment prevalence in populations,[17] as well as for settings with

higher prevalence of refractive error such us Shanxi Province China (76% of visual impairment among people of all ages was in people aged 50+) [18] and Hebei Province China (82% of visual impairment among people aged 7+ was in people aged 50+). [19]

Posterior segment disease was the leading cause of blindness, responsible for 65% of cases. This group of disorders included diabetic retinopathy, glaucoma, ARMD, but attempts was not made to define the exact cause, given that ophthalmic nurses with limited ophthalmic equipment made diagnoses in the field available. The results were similar to the study in the urban area in Cameroon, where posterior segment disease was responsible for 67% of blindness.[16] The high CSC achieved through outreach services and subsidised cataract surgeries supported by mission hospitals was a likely explanation for the relatively low prevalence of cataract blindness and proportionately higher contribution of posterior segment disease in both settings. This pattern of causes is in contrast with hospital based studies and population–based surveys conducted in rural parts of Cameroon, where CSC was relatively low and cataract was the leading cause of blindness.[15, 20] Another possible explanation of the dominance of posterior segment disease as a cause of blindness and VI in this study was that this area of Cameroon had been hyperendemic for onchocerciasis in the past.[21] The dominance of posterior segment disease as a cause of VI in this setting will require further investigation to elucidate the types of posterior segment disease that predominate and therefore define prevention and treatment strategies. It is likely that glaucoma is the leading cause of posterior segment disease here, as it was within the national survey of blindness in Nigeria,[22] which would necessitate a scale up of appropriate services in order to diagnose the condition and provide long-term sustained treatment.

Poor outcome after surgery is an important concern highlighted by the survey, as 31% of eyes had VA<6/60 against the recommended level of no more than 5%.[23] Similar findings were reported in the earlier surveys in Cameroon,[15, 16] as well as elsewhere in West Africa.[24] Urgent attention is therefore needed to further investigate the causes of poor outcomes after cataract surgery and develop strategies for improvement. These strategies may vary by setting, but are likely to include better monitoring of outcomes, better management of eye departments, improved provision of refractive correction after surgery, and more widespread use of biometry.[25, 26]

The prevalence of hearing impairments (30%) and the prevalence of physical impairments (22%) was high among people with VI, as was reported functional difficulties not related to vision. This finding is unsurprising, since these impairments are more common in older people, and are therefore likely to cluster. However, there are few previous similar studies investigating the overlap of VI with other impairments. This evidence emphasises the need to ensure that eye health services are inclusive of people with disabilities. This is important to ensure the fulfilment of the rights of people with disabilities to health care, as stipulated by the United Nations Convention on the Rights of Persons with Disabilities. In addition, since people with disabilities may face difficulties in accessing health care services, it is unlikely that Universal Health Coverage will be achieved, or the Sustainable Development Goal of "Good Health and Wellbeing", without making efforts to ensure that all health services are inclusive of people with disabilities. There are many

changes that can be made to provide inclusive eye health services, although the effectiveness of these has not been formally evaluated. These approaches include providing accessible buildings, training staff on the needs and rights of people with disabilities, and ensuring that information is available in different formats. [6] Incorporating the Short Set Washington Questions within the RAAB survey protocol may be helpful to highlight the high correlation of VI with other functional difficulties, and therefore help to advocate and plan for inclusive eye health services (e.g. accessible facilities and transport).

Self-reported difficulties in vision were closely related to clinically measured VI, with relatively high sensitivity and specificity. A strong positive relationship between visual acuity and self-rated vision has been noted in previous studies. [8, 9] However, these studies also showed that self-rated vision is related to other aspects of visual function besides VA, including contrast sensitivity, stereoacuity and visual fields. These features were not measured in this study, and may explain some of the discrepancies between self-reported and clinically measured visual problems. The poor positive predictive value shows that self-reported vision is inadequate for assessing the prevalence of VI, and clinical measures are still needed in order to determine eye health service needs.

There were a number of limitations to the study. The prevalence of VI was lower than expected, so the precision of the prevalence estimates was less than anticipated, but is accurately reflected by the 95% confidence intervals reported . Diagnoses were made by an ophthalmic nurse in the field with limited equipment available, making

determination of causes of posterior segment disease difficult as well as assessment of visual acuity in young children. Furthermore, there was the potential for selection bias with under-estimation of men of working age and over-sampling of the older population, which may have over-estimated the prevalence of visual impairment. There were also important strengths. The study was population-based and included people of all ages, in contrast to RAAB studies which focus on people aged >50 years. Complementary data were collected on other impairments, including hearing and physical impairment, as well as on self-reported difficulties with seeing.

In conclusion, ophthalmic programmes in Cameroon will need to incorporate control of posterior segment diseases while also working to improve outcomes after cataract surgery. It is also important to ensure that eye health services are designed to be inclusive of people with disabilities, since other impairments are common among people with vision impairment.

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1B: Prevalence and causes of hearing impairment in Fundong District, North West Cameroon

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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?	**Journal of Tropical Medicine and Internationa Health**
When was the work published?	**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**

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
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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)	Coordinated data collection, prepared data for analysis, conducted analyses, provided edits and critical feedback on manuscript

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Prevalence and causes of hearing impairment in Fundong Health District, North-West Cameroon

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Abstract

OBJECTIVE To estimate the prevalence and causes of hearing impairment in Fundong Health District, North-West Cameroon.

METHODS We selected 51 clusters of 80 people (all ages) through probability proportionate to size sampling. Initial hearing screening was undertaken through an otoacoustic emission (OAE) test. Participants aged 4+ years who failed this test in both ears or for whom an OAE reading could not be taken underwent a manual pure-tone audiometry (PTA) screening. Cases of hearing impairment were defined as those with pure-tone average ≥41 dBHL in adults and ≥35 dBHL in children in the better ear, or children under age 4 who failed the OAE test in both ears. Each case with hearing loss was examined by an ear, nose and throat nurse who indicated the main likely cause.

RESULTS We examined 3567 (86.9%) of 4104 eligible people. The overall prevalence of hearing impairment was 3.6% (95% confidence interval [CI]: 2.8–4.6). The prevalence was low in people aged 0–17 (1.1%, 0.7–1.8%) and 18–49 (1.1%, 0.5–2.6%) and then rose sharply in people aged 50+ (14.8%, 11.7–19.1%). Among cases, the majority were classified as moderate (76%), followed by severe (15%) and profound (9%). More than one-third of cases of hearing impairment were classified as unknown (37%) or conductive (37%) causes, while sensorineural causes were less common (26%).

CONCLUSIONS Prevalence of hearing impairment in North-West Cameroon is in line with the WHO estimate for sub-Saharan Africa. The majority of cases with known causes are treatable, with impacted wax playing a major role.

keywords hearing loss, health surveys, sub-Saharan Africa, Cameroon

Introduction

There are an estimated 360 million people worldwide with disabling hearing impairment, that is average hearing level greater than 40 dB in adults or 30 dB in children in the better ear, of whom the majority live in low- and middle-income countries (LMICs) [1]. Sub-Saharan Africa is estimated to be one of the three World Health Organisation (WHO) regions with the highest prevalence of hearing impairment, and most of the causes are believed to be avoidable or treatable [1]. However, these estimates are based on few data; a recent review found only three population-based studies that measured hearing and 14 school screening surveys for the region [2].

Hearing impairment can impact negatively on oral communication skills and may lead to isolation and discrimination [3]. Among those affected, children are less likely to go to school or do not progress as well as their peers, and adults are more likely to be unemployed or working in a low-grade occupation, especially in LMICs [1]. Consequently, hearing loss incurs social and economic costs for the person and the community.

Public health measures can effectively reduce hearing loss or minimise its impact through prevention (e.g. rubella vaccination), treatment (e.g. medical intervention for otitis media) or early diagnosis followed by appropriate interventions (e.g. hearing aids). Few Ear–Nose–Throat (ENT) services are currently available in Africa, and these need to be scaled up [4]. Gathering reliable local information on the extent and main causes of hearing impairment is a crucial step to developing programmes for prevention, identification and management.

We did not find prevalence estimates for hearing impairment in Cameroon. The WHO prevalence estimate for disabling hearing impairment was 4.5% for sub-Saharan Africa region [5]. Previous surveys were conducted in Uganda [6], Madagascar [7] and Nigeria [8], with prevalence estimates for hearing impairment ranging

from 18% to 44%. One study was undertaken in Cameroon to identify the causes of early onset (before age 15) severe/profound hearing loss and found that the dominant causes were vaccine-preventable infectious diseases (41.3%), genetic (14.8%) or unknown causes (32.6%) [9]. Data were not available for causes of hearing loss acquired in adulthood.

The aim of this study was to estimate the prevalence and causes of hearing impairment across all ages in Fundong Health District, North-West Cameroon.

Methods

Study population

This study was undertaken during August-October 2013 in Fundong Health District, North-West Cameroon, as part of a population-based disability survey. The expected prevalence of disabling hearing impairment (i.e. average hearing level ≥41 dB in adults or ≥35 dB in children in the better ear) was conservatively estimated to be 4% [2, 10]. Estimating this prevalence required a sample of 4056, assuming precision of 20%, 95% confidence, a design effect of 1.5% and 20% non-response rate.

We used a two-stage sampling procedure. Fifty-one clusters of 80 people were selected using probability proportionate to size sampling. The 2005 census data were used as the sampling frame. Within clusters, households were selected using compact segment sampling [11]. Existing maps were identified or sketch maps showing the approximate distribution of the population were drawn by team members in collaboration with community leaders. These were divided into segments of approximately 80 people, and one segment was randomly selected. The enumerators visited all households door-to-door in that segment until 80 people were enumerated.

At the household level, a roster was compiled to record the name, age, sex and contact details of each household member. Household members were informed about the survey and invited to attend a previously identified central location over the next 2 days. If an eligible person did not attend the central location, the enumerators visited their household at least twice to encourage attendance. If they were unable to travel to the central location (e.g. due to mobility impairment), the survey team visited them at their household at the end of the second day.

Screening for hearing impairment

Initial screening of all participants was undertaken through an otoacoustic emission (OAE) test in both ears. Participants aged 4 years and above who failed this test in both ears or for whom an OAE reading could not be taken (e.g. discomfort) underwent a manual pure-tone audiometry (PTA) screening, using an Interacoustics screening audiometer (model AS608) with TDH-39 earphones mounted inside circumaural audiocups for extra noise attenuation. The machines were calibrated according to ISO 389-1 and ANSI S3.6 standards. Both tests were conducted in the field in the quietest space available. Environmental noise was measured and recorded on each test using a sound level meter. Hearing thresholds in each ear were measured at 1 kHz, 2 kHz, 4 kHz, 0.5 kHz and again at 1 kHz to ensure consistency of response, and the pure-tone average for each ear across these four frequencies was recorded. Children under age 4 years underwent OAE testing only as PTA is not feasible for this age group.

Cases of hearing impairment were defined as those with pure-tone average ≥41 dBHL in adults [12, 13] (18+ years) and ≥35 dBHL in children [10] (4–17 years) in the better ear, or children under age 4 who failed the OAE test in both ears. The degree of hearing impairment was graded based on pure-tone average in the better ear, as follows: 'moderate' when 41–60 dBHL (18+ years) or 35–60 dBHL (4–17 years); 'severe' when 61–80 dBHL and 'profound' when ≥81 dBHL.

Each person identified as having a hearing impairment was examined by an ENT nurse who indicated the main likely cause based on otoscopy and questions including 'How long has the subject had difficulty hearing?' and 'Does any relative of the subject have difficulty hearing?'. Through the screening and examination questionnaire, we classified causes as those related to:

- conductive hearing loss (potentially reversible), for example wax, foreign body, otitis externa, otitis media and perforation of the tympanic membrane;
- sensorineural hearing loss (permanent), for example infectious diseases, genetic conditions and non-infectious conditions;
- unknown cause.

Self-reported hearing function

Respondents reported whether they had any difficulty in hearing, using the Washington Group Extended Set on Functioning (ESF) questionnaire. The Washington Group ESF is designed to identify participant's functional limitations in core domains such as seeing, hearing and walking, with answers given on a four-point scale: 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'cannot do at all' [14, 15].

Training

Three survey teams each received 10 days training. Ear–Nose–Throat nurses received a week of training in diagnoses by an experienced ENT surgeon in the WHO survey tool protocol. Their diagnoses were compared with that of the ENT surgeon. The interobserver variation for all measurements was assessed to ensure it was of an acceptable standard (i.e. Kappa ≥0.6).

Data analysis

Data were analysed using STATA version 12.0 (Stata Corp, College Station, Texas, USA). The 'svy' command was used to derive prevalence estimates accounting for the cluster sampling design. Sensitivity, specificity, predictive values positive and negative were estimated comparing clinical measures to self-reported hearing loss. First, using a broader definition of hearing loss (i.e. 'some' or more difficulty hearing reported) and then using a more restrictive definition of hearing loss (i.e. 'a lot' or more difficulty hearing).

Ethical approval and consent

Ethical approval was obtained from the National Ethics Committee for Research in Human Health (CNERSH, Cameroon), the Cameroon Baptist Convention Health Board Institutional Review Board and the London School of Hygiene & Tropical Medicine. Referral services available in the region were mapped in advance to ensure appropriate onward referral for any individuals identified with unmet healthcare needs.

All participants were read an information sheet about the study and given the opportunity to ask questions. If they agreed to participate, written/finger print consent was taken. For children under age 21 years, a caregiver was required to provide consent and to remain present throughout the screening. Participants who screened positive for hearing impairment were examined by a clinician and referred for ear and hearing care services (as appropriate) and to a community-based rehabilitation (CBR) or self-help group programme for additional support in education, livelihoods, benefits etc.

Results

Population and demographics

A total of 4104 people were enumerated for the population-based survey, of whom 3567 were screened for hearing impairment, giving a response rate of 86.9%. Among non-participants, only 17 (0.4%) refused and 520 (12.7%) were unavailable. Comparing to those examined (mean age 24.4 years), refusers were older (39.4, $P < 0.001$) as were those not available (28.1 years, $P < 0.001$). The groups did not differ by gender (examined: 59.2% female; refusers: 64.7%, $P = 0.65$; not available: 56.0%, $P = 0.17$).

The sample (2013) was compared to a demographic projection based on Cameroon Census 2005 and found to somewhat oversample women, infants (0–9 years) and older groups (60+ years), and to undersample young adults (20–39 years) particularly among males (Table 1).

Hearing screening protocol outcomes

From 3567 screened, the complete screening protocol was undertaken for 3353 people (94.0%), 97.6% of

Table 1 Age and gender distribution of district* and study sample population, Fundong Health District, North-West Cameroon, 2013

	Men				Women				All			
	District		Study sample		District		Study sample		District		Study sample	
Age group (year)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
All	909 933	(47.9)	1455	(40.8)	990 614	(52.1)	2112	(59.2)	1 900 547	(100.0)	3567	(100.0)
0–9	285 644	(31.4)	609	(41.9)	279 340	(28.2)	630	(29.8)	564 984	(29.7)	1239	(34.7)
10–19	258 047	(28.4)	399	(27.4)	257 261	(26.0)	423	(20.0)	515 308	(27.1)	822	(23.0)
20–29	136 854	(15.0)	77	(5.3)	174 712	(17.6)	307	(14.5)	311 566	(16.4)	384	(10.8)
30–39	83 977	(9.2)	70	(4.8)	107 390	(10.8)	197	(9.3)	191 367	(10.1)	267	(7.5)
40–49	55 672	(6.1)	67	(4.6)	70 492	(7.1)	152	(7.2)	126 164	(6.6)	219	(6.1)
50–59	38 749	(4.3)	61	(4.2)	47 397	(4.8)	146	(6.9)	86 146	(4.5)	207	(5.8)
60–69	28 845	(3.2)	60	(4.1)	32 158	(3.2)	127	(6.0)	61 003	(3.2)	187	(5.2)
70–79	15 709	(1.7)	66	(4.5)	14 930	(1.5)	86	(4.1)	30 639	(1.6)	152	(4.3)
80+	6436	(0.7)	46	(3.2)	6934	(0.7)	44	(2.1)	13 370	(0.7)	90	(2.5)

*Based on Cameroon Census 2005 demographic projection for North-West Region, 2014.

people aged 4+ years and 70.7% of children under age 4 years. Incomplete protocols occurred due to environmental noise (e.g. loud rain), discomfort or individual-level cognitive difficulties. Participants with incomplete protocols were considered cases or non-cases depending on their outcome patterns (Figure 1). Specifically, as only eight (2.4%) of 336 children <4 years who underwent the OAE screen failed this test (328 pass and 8 fail), we classified children with incomplete OAE as non-cases for hearing impairment. Conversely, as of the 297 people aged 4+ years who failed OAE, 90 (30.3%) also failed in PTA, we classified those who had failed OAE but with incomplete PTA as cases. Finally, when both OAE and PTA were incomplete, we classified participants as non-cases.

Prevalence of hearing impairment

The overall prevalence of hearing impairment was 3.6% (95% confidence interval [CI]: 2.8–4.6; Table 2). The prevalence was low in people aged 0–17 (1.1%, 0.7–1.8%) and 18–49 (1.1%, 0.5–2.6%) and then rose sharply in people aged 50+ (14.8%, 11.7–19.1%). Overall, 74% of cases of hearing impairment were in people aged 50+. There was little difference in the prevalence between men and women.

Among cases, the degree of hearing impairment was assessed for those aged 4+ years who completed the whole protocol (n = 100). The majority were classified as moderate (76%), followed by severe (15%) and profound (9%). The overall prevalence of hearing impairment by severity was 2.5% (1.9–3.2%) for moderate, declining to 0.5% (0.3–0.8%) and 0.3% (0.1–0.6%) for severe and profound degree, respectively, with no statistical difference across gender groups (Table 3).

Causes of hearing impairment

Overall, the main likely causes of hearing impairment were unknown for 37% of the cases (n = 47), while another 37% (n = 47) were detectable causes related to conductive hearing loss and 26% (n = 33) were causes usually related to sensorineural hearing loss. Within these two groups of causes, impacted wax in the ear canal (31.5% of overall cases, n = 40) and age-related hearing loss (22.8%, n = 29) were the most common, respectively. The pattern of likely causes changed across age groups, with the largest proportion corresponding to

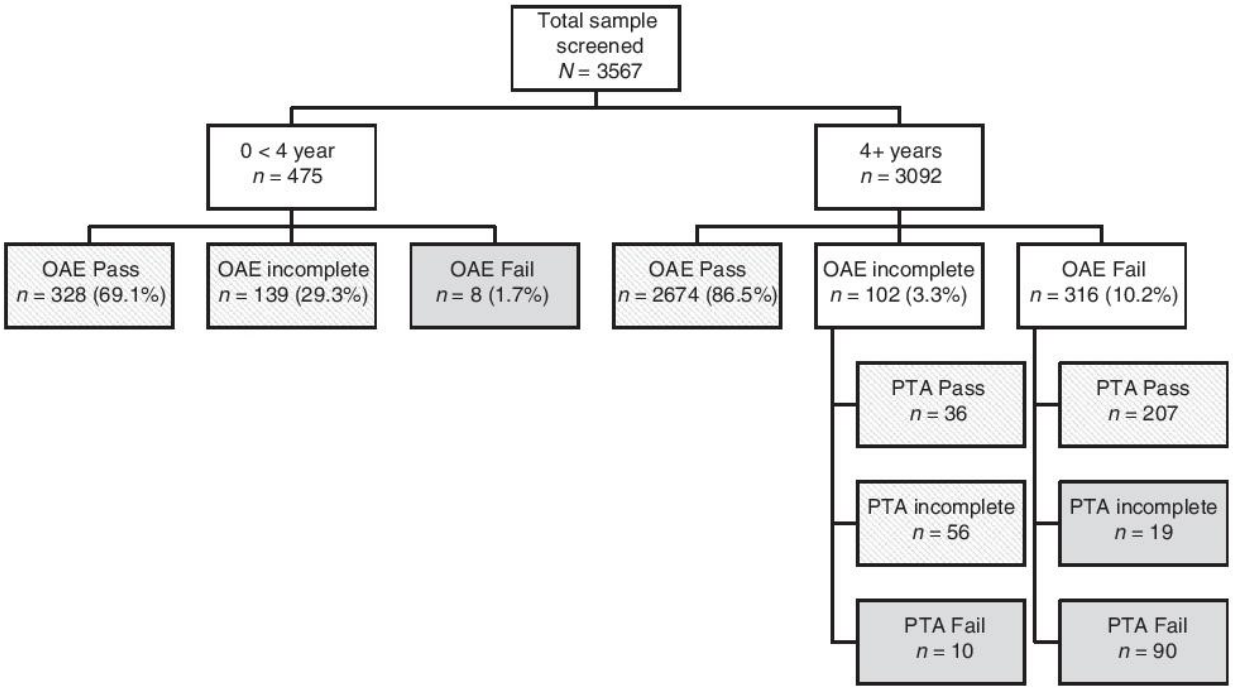

Figure 1 Flow chart of hearing screening protocol outcomes, Fundong Health District, North-West Cameroon, 2013. OAE: otoacoustic emission; PTA: pure-tone audiometry screening. Striped boxes indicate non-cases, and grey filled boxes indicate cases of hearing impairment for this study.

Table 2 Prevalence of hearing impairment by age and gender group, Fundong Health District, North-West Cameroon, 2013

		Hearing impairment*		
	n	Cases	Prevalence (%)	95% CI†
All	3567	127	3.6	(3.0, 4.2)
Age group (year)				
0–17	1950	22	1.1	(0.7, 1.8)
18–49	981	11	1.1	(0.5, 2.6)
50+	636	94	14.8	(11.7, 19.1)
Gender				
Men	1455	44	3.0	(2.2, 4.2)
Women	2112	83	3.9	(2.9, 5.4)

*Defined as those with pure-tone average ≥41 dBHL in adults (18+ years) and ≥35 dBHL in children (4–17 years) in the better ear, or children under age 4 who failed the otoacoustic emission test in both ears.
†All estimates adjusted for sample design.

unknown causes among children and to impacted wax among adults under 50 years of age (Figure 2). Among those aged 50+ years, ageing, unknown causes and impacted wax showed similar proportions.

Self-reported hearing function *vs.* clinically measured hearing impairment

Prevalence of hearing loss based on self-report was higher than the estimate based on PTA when defined as 'some' or more difficult hearing (14.1%) and lower when defined as 'a lot' or more difficult hearing (1.1%; Table 4). The option 'cannot do at all' was not reported by any participant/proxy. Sensitivity was 67% and specificity was 88% when comparing clinical measures and a broader definition of self-reported hearing loss (i.e. 'some' or more difficulty category) and 22% and 99.6%, respectively, for the more restrictive definition (i.e. 'a lot' or more difficulty). Likewise, positive and negative predictive value were estimated as 16% and 99%, and 65% and 97%, respectively, for the broader and more restrictive definition of hearing loss based on self-report.

Discussion

This population-based survey was conducted to estimate the prevalence and likely causes of hearing impairment across all ages in North-West Cameroon. The overall prevalence of disabling hearing impairment was 3.6% (95% CI: 2.8–4.6). The prevalence was relatively low at 1.1% among of children (<18 years) and adults (18–49 years) and rose rapidly to a level of 14.8% of those people aged 50+, so that the vast majority of cases were in the oldest age group. Hearing impairment was mostly moderate with few cases classified as severe or profound. In about two-fifths of cases, we could not identify the main likely cause, but for those cases where we could identify, they were mostly related to the external or to the middle ear. Among participants for whom a cause could be detected, impacted wax in the ear canal was the commonest cause, especially among adults (18–49 years). Age-related hearing loss was important among people aged 50+. Among children, the unknown causes prevailed.

Prevalence of hearing impairment

Three previous surveys of hearing impairment were identified for sub-Saharan Africa [2], all of which included people of all ages. All used lower thresholds for defining hearing impairment than we did, including 30 dBHL in

Table 3 Prevalence of hearing impairment by severity according to gender group among people aged 4+ years, Fundong Health District, North-West Cameroon, 2013

		Degree of hearing impairment*					
		Moderate		Severe		Profound	
	n	Cases	P % (95% CI)†	Cases	P % (95% CI)†	Cases	P % (95% CI)†
All	3092	76	2.5 (1.9, 3.2)	15	0.5 (0.3, 0.8)	9	0.3 (0.1, 0.6)
Gender							
Men	1238	26	2.1 (1.4, 3.0)	5	0.4 (0.2, 1.0)	2	0.2 (0.04, 0.7)
Women	1854	50	2.7 (1.9, 3.9)	10	0.5 (0.3, 1.1)	7	0.4 (0.2, 0.9)

P, Prevalence.
*Based on pure-tone average in the better ear: moderate when 41–60 dBHL (18+ years) or 35–60 dBHL (4–17 years); severe when 61–80 dBHL and profound when ≥81 dBHL.
†All estimates adjusted for sample design.

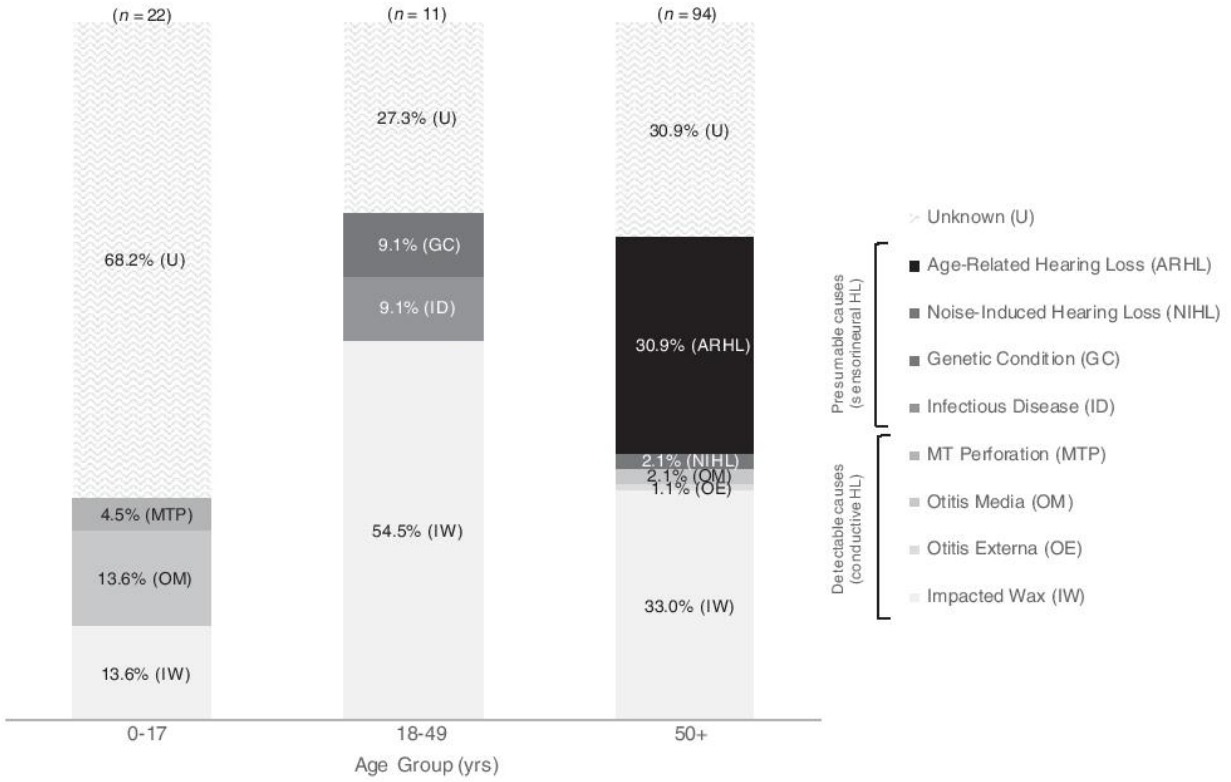

Figure 2 Main likely causes of hearing impairment by age group, Fundong Health District, North-West Cameroon, 2013 (n = 127).

Table 4 Relationship between self-reported hearing function and clinically measured hearing impairment, Fundong Health District, North-West Cameroon, 2013

		Do you have difficulty hearing?†‡§		
Degree of hearing impairment based on PTA	n = 3017*	None	Some	A lot
No hearing impairment	2906	2549 (87.7%)	345 (11.9%)	12 (0.4%)
Moderate	76	32 (42.1%)	34 (44.7%)	10 (13.2%)
Severe	15	1 (6.7%)	8 (53.3%)	6 (40.0%)
Profound	9	0 (0.0%)	3 (33.3%)	6 (66.7%)
Any hearing impairment	100	33 (33.0%)	45 (45.0%)	22 (22.0%)

PTA, pure-tone audiometry.
*Considering all participants 4+ years old except 75 with incomplete PTA.
†Eleven Washington Group responses missing.
‡Responses from proxy for children.
§The option 'Cannot do at all' was not reported by any participant/proxy.

Uganda [6] and Madagascar [7] and 25 dBHL in Nigeria [8]. Coherently, all three surveys reported higher prevalence estimates than found here, ranging from 18% in both Nigeria and Uganda, to 44% in Madagascar. Although we have not fully followed the WHO protocol, our estimate of 3.6% disabling hearing impairment is in line with WHO estimate of 4.5% for sub-Saharan Africa region [5], which is consistent with the higher cut-offs we adopted. This similarity was yet more evident when comparing WHO estimate of 6.4% disabling hearing impairment among adults (15+ years of age) with our estimate of 6.5% (18+ years of age; data not shown). Our

estimate of 1.1% among children was slightly lower than the WHO estimates (1.9%). However, the WHO estimate for children is based on a threshold of 30 dBHL while in our study, we adopted a slightly higher threshold (35 dBHL) following the Global Burden of Disease (GBD) expert group definition for hearing impairment [10].

Causes of hearing impairment

Causes of hearing loss were difficult to determine in this field setting, and consequently, 37% of cases were of unknown causes. This concurs with previous prevalence studies, with an average proportion of 35% of unknown causes in Africa [2]. Specifically in Cameroon, a previous study found causes were unknown for 33% of 582 people with early onset (before age 15) severe/profound hearing loss [9].

In this study, where causes could be determined, more than a half was conductive which is potentially reversible by treatment. This is consistent with findings in other settings in Africa [2]. Within these causes, impacted wax was the most common in this population, which can be easily treated or prevented through primary healthcare services.

Although not all forms of conductive hearing loss show visible signs via otoscopy (e.g. otosclerosis), it is plausible to suggest that in this study, the greater proportion of unknown causes is related to inner ear aetiologies, which cannot be detected via otoscopy. Inner ear lesions lead to a sensorineural, permanent hearing loss, highlighting needs for hearing aids, rehabilitation, educational and social support.

Self-reported hearing function *vs.* clinically measured hearing impairment

Overall hearing loss based on self-report either overestimated or underestimated the clinical impairment prevalence depending on the degree of difficulty taken as cut-off point. Regardless of the definition, specificity and predictive negative values were high, as expected in low-prevalence settings. Accuracy estimates suggest that a self-reported functional approach alone will not identify all individuals with moderate or worse hearing impairment.

There were a number of limitations to the study design that need to be taken into account. The prevalence of hearing impairment was lower than expected, so that the study was potentially underpowered. Using only OAE to screen children under age 4 may have led to incorrect classification of cases/non-cases [16], although OAE accuracy measures for identifying hearing impairment have shown good performance, including low rates of false-positive and false-negative results [16, 17]. Despite the ENT nurses' training in diagnoses, these were made in the field with limited equipment available, which made it difficult to determine the causes reliably, and consequently, more than one-third of cases were of unknown aetiology. The addition of tympanometry on site would have helped to better differentiate between conductive and sensorineural hearing loss. The ENT nurse indicated only the main likely cause; however, more than one cause can be simultaneously related to a hearing impairment. There were also important strengths. The study was population based and included people of all ages. Hearing loss was measured using clinical instruments, and a clinician was available in the field to make diagnoses.

The impact of hearing impairment is potentially large on society, individuals affected and their families [1, 18]. Hearing loss is the fifth leading cause of years lived with disability according to the GBD Study 2013 [19]. In Cameroon, most cases with known causes could have been prevented or treated, with appropriate referral to a specialist. In cases of permanent hearing loss, hearing aids and rehabilitation can improve communication abilities and enable better quality of life and future achievements in life. However, human resources for health care are poorly available in Cameroon. The national estimate of the health workforce density is 1.3 per thousand population [20]. Indeed, among the WHO regions, Africa stands with the lowest cadres of ear and hearing human resources (ENT specialists, audiologists and speech therapists) with less than one of each per million population where data are available [21]. In LMICs, global initiatives are needed to help build national strategies to prevent hearing impairment and to minimise its adverse effects.

In the context of an overall lack of population-based epidemiological data on hearing impairment and its causes [21], this study adds to the knowledge providing data from a country in one of the most affected and least studied regions – sub-Saharan Africa. This is an essential step towards developing strategic plans for prevention, identification and management of cases in Cameroon. In the future, new research efforts should address the development of national hearing care infrastructure and human resources.

Acknowledgements

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1C: Prevalence and causes of musculoskeletal impairment in Fundong District, North West Cameroon: Results of a population based survey

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	Islay Mactaggart
Principal Supervisor	Sarah Polack
Thesis Title	Measuring Disability in Population-Based Surveys: The relationship between clinical impairments, self-reported functional limitations and equal opportunities in two Low and Middle Income Country settings

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.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	The Journal of Tropical Medicine and International Health
Please list the paper's authors in the intended authorship order:	Tracey Smythe, Islay Mactaggart, Hannah Kuper, Joseph Oye, Nana Christopher, Christopher Lavy, Sarah Polack
Stage of publication	**Not yet 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)	Coordinated data collection, prepared data for analysis, conducted analyses, provided edits and critical feedback on manuscript

Student Signature: [redacted] Date: 30.03.2017

Supervisor Signature: [redacted] Date: 30.03.2017

Prevalence and causes of musculoskeletal impairment in Fundong District, North West Cameroon: Results of a population based survey

Authors: Tracey Smythe, Islay Mactaggart, Hannah Kuper, Joseph Oye, Nana Christopher Sieyen, Christopher Lavy, Sarah Polack

Abstract

Objectives

Epidemiological data on musculoskeletal conditions is lacking in low- and middle-income countries. The objective of this survey was to estimate the prevalence and causes of musculoskeletal impairment in Fundong Health District, North-West Cameroon.

Methods

Fifty-one clusters of 80 people (all ages) were selected using probability proportionate to size sampling. Households within clusters were selected by compact segment sampling. Six screening questions were asked to identify participants likely to have a musculoskeletal impairment (MSI). Participants screening positive to any screening question underwent a standardized examination by a physiotherapist to assess presence, cause, diagnosis and severity of impairment.

Results

In total, 3,567 of 4,080 individuals enumerated for the survey were screened (87%). The all-age prevalence of MSI was 11.6% (95% CI: 10.1-13.3). Prevalence increased with age, from 2.9% in children to 41.2% in adults 50 years and above. The majority of MSI cases (70.4%) were classified as mild, 27.2% as moderate and 2.4% as severe. Acquired non-trauma comprised 67% of the diagnoses. The remainder included trauma (14%), neurological (11%), infection (5%) and congenital (3%). The commonest individual diagnosis was degenerative joint disease (43%). Over one third (38%) of individuals with MSI had never received medical care or rehabilitation for their condition.

Conclusions

This survey contributes to the scarce epidemiological data on MSI in low- and middle-income countries. Nearly half of adults aged over 50 years had an MSI. There is a need to address the treatment and rehabilitative service gap for people with MSI in Cameroon.

Introduction

Musculoskeletal disorders are one of the leading contributors to loss in healthy life expectancy (1) and include conditions that can affect muscles, bones and joints, such as degenerative joint diseases and bone fractures. People with disabilities, of which physical disability is one of the most common forms (2), frequently experience exclusion from education and employment opportunities (3) and barriers to accessing health and rehabilitation services (4) and are at greater risk of poverty (3). A study of in Malawi found that children with MSI experienced indignity, for example through bullying, exclusion from core activities and pain and that those with severe MSI were at increased risk of hunger (5) .

The Bone and Joint Decade (2000 – 2010) (6), endorsed by the United Nations and the World Health Organisation (WHO), was established to raise awareness about the impact that musculoskeletal conditions have on communities. Despite this, there is lack of data on prevalence and causes of MSI in low and middle income countries (LMIC) (7). This reflects, in part, the complexities of MSI and lack of agreement in case definition and survey methodology (2). Estimates of disability in LMIC have often relied on self-report of disability asked as a single question, which is likely to lead to underestimates (8) or reported functional limitations (9) which may not capture all MSI. Surveys using objective standardized screening criteria to generate reliable and comparable estimates of prevalence, cause and severity of MSI are lacking (10). These data are needed to understand and address the health and rehabilitation service needs of persons with MSI.

To address this gap, the Rapid Assessment of MSI (RAM) was developed as an all-age population based survey methodology to estimate the prevalence and causes of MSI, providing data to help plan and advocate for medical, rehabilitation and other services (10). A survey using this method estimated the prevalence of MSI as 5.2% in Rwanda (11). These data are needed in other LMIC settings to provide locally relevant data for planning services and to build the global evidence base with regards to the epidemiology of MSI.

The aim of this study is to estimate the prevalence and causes of musculoskeletal impairments in Fundong Health District, North West Cameroon.

Methods

Sampling

The population-based survey included people of all ages. Data collection was undertaken during August-October 2013 in Fundong Health District, North West Cameroon. The expected prevalence of MSI was estimated to be 4% (7, 11). This required a sample of 4,056 individuals and assumed a precision of 20%, 95% confidence, a design effect of 1.5 and 20% non-response.

A two-stage sampling procedure was used. Fifty-one clusters of 80 people were selected using probability proportionate to size sampling. The 2005 census data was used as the sampling frame. Compact segment sampling was used to select households within clusters. Existing maps or sketch maps drawn by team members in collaboration with community leaders showing the approximate distribution of the population were divided into segments of approximately 80 people and one segment was randomly selected. The enumerators visited all houses door-to-door in that segment until 80 people were included.

At the household, the name, age, sex and contact details of each household member was recorded. Household members were informed about the survey and invited to attend a previously identified central location over the next two days. If an eligible person did not attend the central location the enumerators visited their household at least twice to encourage attendance. If they were unable to travel to the central location (e.g. due to mobility impairment) the survey team visited them at their house at the end of the second day.

Screening for musculoskeletal impairment

We used the RAM methodology for this study (10). Six initial screening questions were used to assess a) difficulty using the musculoskeletal system, b) use of mobility aids, and c) whether the participant considered any of their body parts to be misshapen. This screening tool has been shown to have high sensitivity (99%) and specificity (97%) (10). A physiotherapist examined participants with a positive response to any screening question. The examination included standardised observation of activities (e.g. walking and picking up small items) to assess functioning. The physiotherapist also examined the affected area. The diagnoses were categorised as congenital, traumatic, infective, neurological, or acquired non traumatic non infective and the clinician assigned a specific diagnosis with these categories. Up to two diagnoses were permissible per identified case of MSI. Aetiology was recorded where it was known by asking the participants about when and how the impairment developed. Based on these examinations, the participant was categorised as having either mild, moderate or severe musculoskeletal impairment. Participants were also asked about treatment or rehabilitation

that they had received for their impairment and the physiotherapists made referral recommendations, with consideration to available services in Cameroon.

Self-reported functional difficulty

In addition to clinical screening, participants were also screened for self-reported functional limitations using the Washington Group (WG) extended set (adult or child version) (12, 13) For children under eight years, the primary caregiver was interviewed as a proxy. This questionnaire includes a domain on mobility which for children asks: "Compared with children of the same age, does [name] have difficulty walking?"; and for adults: "Do you have difficulty walking or climbing steps?". These questions are assessed using a four-point response scale ("no difficulty", "some difficulty", "a lot of difficulty" or "cannot do at all"). We compared these responses with clinically measured MSI.

Training

Three survey teams received 10 days training. The inter-observer variation for the measurement of MSI level and diagnosis of cause was assessed to ensure an acceptable standard (i.e. Kappa ≥0.6). The questionnaires were cognitively tested and checked for context relevance, and the survey protocol was pilot tested for suitability.

Data analysis

Data were double entered into an access database and were analysed using STATA 14.0 (StataCorp LP, College Station, Texas). The confidence around the prevalence estimates accounted for the cluster sampling design. Sensitivity, specificity and positive and negative predictive values were estimated in the comparison of clinical measures to self-reported mobility difficulties. Two predictive values were estimated. The first used a broad definition of mobility difficulties (i.e. "some" or "more" difficulty with mobility reported). The second used a more restrictive definition (i.e. "a lot" or "more" difficulty).

Ethics

Ethical Approval for the study was granted by the National Ethics Committee for Research in Human Health (Cameroon), the Cameroon Baptist Convention Health Board Institutional Review Board and the London School of Hygiene & Tropical Medicine.

All participants were read an information sheet about the study and given the opportunity to ask questions. If they agreed to participate, written/finger print consent was taken. For children <21 years, a caregiver was required to provide written/finger print consent and to remain present throughout the screening as per national requirements.

Referral services available in the region were mapped pre-emptively to ensure appropriate onward referral for any individuals identified with unmet healthcare needs. All people identified as having an impairment in the study, regardless of health or other need, were referred to a Community-based Rehabilitation (CBR) or Self Help Group program for additional support. Clinical team members distributed basic medicines where appropriate.

Results

A total of 4,080 individuals (51 clusters of 80 people) were enumerated for the population-based survey, of whom 3,567 were screened (response rate 87.4%). Among non-responders 0.5% (n=17) refused and 12.7% (n=521) were unavailable. Mean age was higher amongst non-responders (39.4 years 95% CI: 26.1 - 52.8 amongst refusers, 28.1 years 95% CI: 26.4 - 29.7 amongst those who were unavailable) compared to people who were examined (24.4 years 95% CI: 23.6 - 25.1). The proportion of male and female participants was similar across those examined and those unavailable, but refusers were more likely to be female (those examined 59% female, unavailable 56% female and refused 65% female).

The age distribution of the study population was similar to that of the national population according to the census data but females were over represented in the sample (Table 1).

Of the 3,567 individuals screened, 415 cases of MSI were identified giving an all-age MSI prevalence of 11.6% (95% CI: 10.1 – 13.3) (Table 2). The prevalence of MSI increased with age from 2.9% (95%CI: 1.9 – 4.3) among children aged 0-17 years to 41.2% (95%CI:36.1 – 46.4) in individuals aged 50 years or higher (Table 2). The prevalence of MSI in women was higher 12.9% (95%CI: 11.2 – 14.9) than men 9.8% (95%CI: 8.0 – 11.8) but this difference was not statistically significant. The majority of MSI cases (70.4%) were classified as mild, 27.2% as moderate and 2.4% as severe.

Extrapolating these findings to the population of Cameroon, we estimate there are a total of 35,000 people per million population with a moderate or severe MSI and 116,000 people per million population (95% CI:101,000-133,000) with any MSI in this setting. By age there are an estimated; 15,950 children with MSI aged 0-17 years (95% CI:10,450 – 23, 650), 34,920 aged 18-50 years (95%CI: 27,000 – 44, 640) and 37,080 adults > 50 years (95%CI: 32,490 – 41,760).

Table 1 Age and gender distribution of district (census) and study sample population

	Males		Females		Total	
Age group	**District***	**Study sample**	**District**	**Study sample**	**District**	**Study sample**
0-9	285,644 (31.4%)	609 (42%)	279,340 (28.2%)	630 (30%)	564,984 (29.7%)	1,239 (35%)
10-19	258,047 (28.4%)	399 (27%)	257,261 (26.0%)	423 (20%)	515,308 (27.1%)	822 (23%)
20-29	136,854 (15.0%)	77 (5%)	174,712 (17.6%)	307 (15%)	311,566 (16.4%)	384 (11%)
30-39	83,977 (9.2%)	70 (5%)	107,390 (10.8%)	197 (9%)	191,367 (10.1%)	267 (7%)
40-49	55,672 (6.1%)	67 (5%)	70,492 (7.1%)	152 (7%)	126,164 (6.6%)	219 (6%)
50-59	38,749 (4.3%)	61 (4%)	47,397 (4.8%)	146 (7%)	86,146 (4.5%)	207 (6%)
60-69	28,845 (3.2%)	60 (4%)	32,158 (3.2%)	127 (6%)	61,003 (3.2%)	187 (5%)
70-79	15,709 (1.7%)	66 (5%)	14,930 (1.5%)	86 (4%)	30,639 (1.6%)	152 (4%)
80+	6,436 (0.7%)	46 (3%)	6,934 (0.7%)	44 (2%)	13,370 (0.7%)	90 (3%)
Total	909,933 (47.9%)	**1,455 (40.8)**	990,614 (52.1%)	**2,122 (59.2%)**	1,900,547 (100%)	**3,567**

NB: * Cameroon Census 2005 demographic projection for North West Region 2014

Table 2 Prevalence of musculoskeletal impairments by age, gender and impairment severity

	Total		0-17 years*		18-49 years		50+ years		Male		Female	
	N	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**
Any MSI	415	11.6 (10.1 – 13.3)	58	2.9 (1.9-4.3)	95	9.7 (7.5 – 12.4)	262	41.2 (36.1 – 46.4)	142	9.8 (8.0 – 11.8)	273	12.9 (11.2 – 14.9)
Mild	292	8.2 (6.8 – 9.8)	32	1.6 (1.1 – 2.5)	67	6.8 (5.1 – 9.2)	193	30.3 (25.3 – 35.9)	100	6.9 (5.2 – 9.0)	192	9.1 (7.6 – 10.9)
Moderate	113	3.2 (2.5-4.0)	24	1.2 (0.7-2.1)	24	2.4 (1.6-3.8)	65	10.2 (7.8-13.3)	39	2.7 (1.9-3.8)	74	3.5 (2.7-4.6)
Severe	10	0.3 (0.2-0.5)	2	0.1 (0.03-0.4)	4	0.4 (0.2-1.1)	4	0.6 (0.2-1.7)	3	0.2 (0.07-0.6)	7	0.3 (0.2-0.7)

Age of impairment

Among all individuals with MSI, just ove two-thirds of the impairment (68%) was aquired above the age of 50 years, with 6% present at birth. Among the children with MSI, 30% were born with their condition, 28% aquired the impairment before they were 5 years and the remainder after 5 years of age. Among adults aged 18-50 years with MSI, just under half (47%) aquired their impairment during their adult years (i.e. >17years) and 7% were born with the impairment. Among adults aged >50 years with MSI, the vast majority (96%) had developed their impairment above the age of 40 years.

Diagnoses

The causes of MSI are shown in Table 3. There were a total of 455 diagnoses for the 415 participants with MSI. Overall, 67% of all MSI diagnoses were acquired non-traumatic non-infective causes, 14% were due to trauma, 11% had neurological causes, 5% were due to infection and 3% were congenital. Extrapolating these estimates to the total population of Cameroon, suggests there are approximately 1,736,000 MSI diagnoses in the country.

Table 3. Cause of MSI in survey, and extrapolated to population of Cameroon

Diagnosis	Number	Total in category (%)		Extrapolated total number of diagnostic category to nearest 1,000 (95%CI)
Total Congenital		**14**	**3%**	**52,000 (42,000-65,000)**
Polydactyly	2			
Congenital absence of all/part of tibia	1			
Clubfoot	2			
Other congenital abnormality of lower limb	6			
Congenital deformity of thoracolumbar spine	1			
Multiple congenital abnormalities	2			
Total Infective		**21**	**5%**	**87,000 (69,000-108,000)**
Joint infection	5			
Bone infection	3			
Skin/soft tissue infection/wound	13			
Total trauma		**65**	**14%**	**278,000 (221,000-346,000)**
Burn contracture	7			
Fracture malunion	11			
Spinal injury	1			
Recurrent/chronic dislocation	1			
Post traumatic joint stiffness	3			
Tendon Problem	6			
Muscle problem	4			
Peripheral nerve problem	4			
Amputation	10			
Other trauma	18			
Total neurological		**51**	**11%**	**208,000 (166,000 -260,000)**
Epilepsy	11			
Developmental delay	6			
Cerebral palsy	8			

Paraplegia	1			
Hemiplegia	5			
Peripheral nerve palsy/facial weakness	8			
Polio	1			
Other neurological	11			
Total Acquired non-traumatic		**304**	**67%**	**750,000 (358,000-845,000)**
Degenerative joint diseases	196			
Non-infective non traumatic joint disease	4			
Knock knees	5			
Other joint deformity	3			
Bone/skin/soft tissue tumour	7			
Scoliosis	1			
Spinal pain limiting spine function	41			
TB/spine infection	1			
Limb pain	8			
Lymphoedema	2			
Other acquired non-traumatic	36			
Total		**455**		**1,736,000 (1,383,000-2,169,000)**

Prevalence and MSI diagnoses varied by age (figure 1). Among the children aged 0-17 years, neurological, trauma and infective diagnoses were the most common. With increasing age there was a proportional increase in MSI due to acquired non-traumatic causes so that 83% of the diagnoses for older adults (aged >50 years) were in this category.

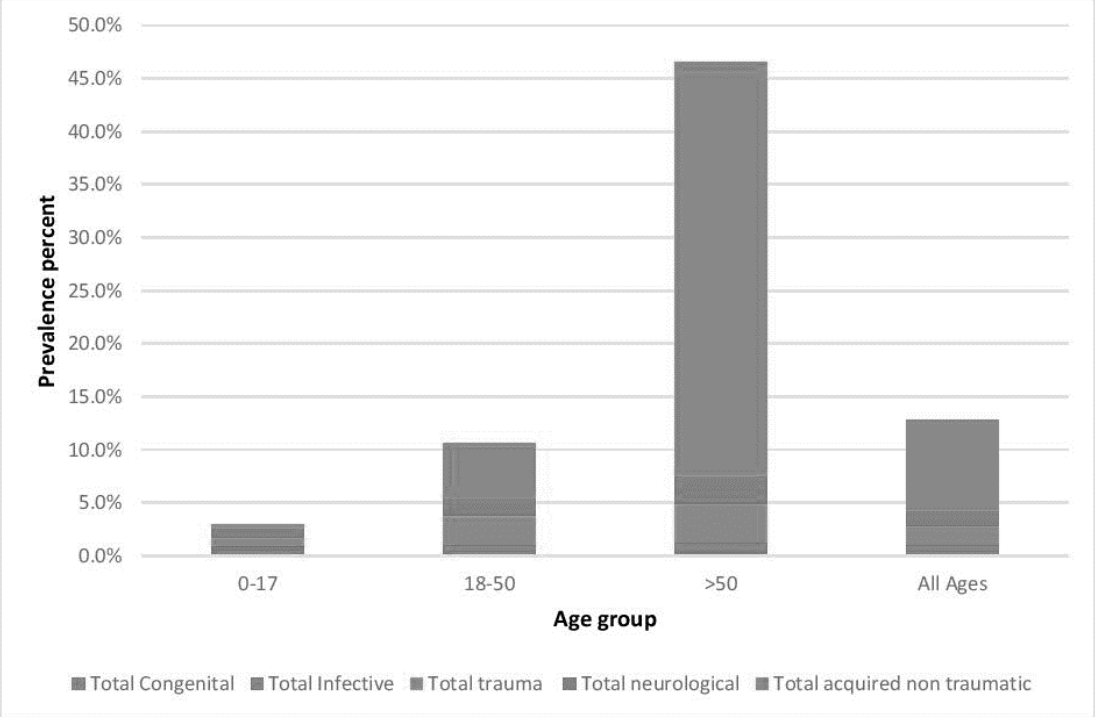

Figure 1 Diagnostic categories of MSI, by age group

Aetiology

Aetiology was unknown for the majority (59%) of the individuals with MSI. Fifteen percent of MSI was due to trauma, 8% was congenital (without family history) and 6% was due to infection. Other aetiologies that include iatrogentic (1%), neoplasm (1%), family history (2%), developmental (1%) and perinatal hypoxia (0.3%) were relatively rare.

Treatment

Participants were asked about previous interventions that they had received relating to their impairment. The intervention that was most commonly reported was medication (49%) followed by traditional medicine (18%), mobility aids (11%) and physiotherapy (7%). Over one third of individuals with MSI (38%) reported they had never received any medical or rehabilitation services.

At least one medical or rehabilitation services was recommended for 74% of individuals with MSI by the clinician during the survey. Medication (66%) and physiotherapy (65%) were the most commonly recommended treatments, followed by mobility aids (30%), surgery (9%) and long-term care (e.g. in a hospital) (9%).

Table 5. Recommended intervention for individuals with MSI

	Intervention previously received[ab]		Intervention recommended[ac]	
	N	**%**	**N**	**%**
None	148	38%	98	26%
Medication	192	49%	246	66%
Plaster/Splintage	10	3%	16	4%
Physiotherapy	26	7%	244	65%
Special Seating	0	0%	3	1%
Mobility aid	45	11%	114	30%
General assistive aid	9	2%	11	3%
Orthosis/prosthesis	0	0%	6	2%
Wheelchair	2	1%	4	1%
Surgery	11	3%	33	9%
Long-term care (e.g. hospital/institution)	14	4%	33	9%
Traditional medicine	69	18%	0	0%
Other:	9	2%	23	6%

[a] More than one intervention could be recommended for each person, hence totals equal more than 100%

[b] data were missing for 42 individuals and they were excluded from analysis.

[c] Data were missing from 23 individuals and they were excluded from analysis

Among the 415 people with a MSI, 8% had a vision impairment, 15% had a hearing impairment and 2% had epilepsy. Overall 21% of people with a MSI also had at least a vision or hearing impairment or epilepsy.

Comparison of clinically measured and self-reported difficulties with mobility

Of the 406 participants with clinically assessed MSI (mild, moderate or severe) and Washington Group responses in the domain of "walking/climbing", 286 reported 'some' or 'more' problem with mobility (sensitivity = 70%) using the Washington Group (WG) questionnaire. Of the 2,902 people who did not have an MSI according to the clinical assessment, 2,346 reported no difficulty with mobility (specificity: 81%). Of the 2,465 who reported no difficulty, 2,346 also had no MSI (negative predictive value: 95%). Among the 841 who reported 'some' or 'more' difficulty, 286 had a clinically assessed MSI (positive predictive value: 34%). If a narrower self-reported definition of 'a lot of difficulty' or greater is used, the sensitivity decreased to 18%, specificity increased to 99%, and positive and negative predictive values were 72% and 90% respectively.

Table 6: Relationship between clinically assessed impairment and self-reported difficulties with mobility

	Self-reported difficulties			
Clinically assessed MSI	**None N (%)**	**Some N (%)**	**A lot N (%)**	**Extreme/ Cannot do N (%)**
No MSI (n=2902)	2,346 (81%)	526 (18%)	29 (1%)	0
Mild (n=287)	90 (32%)	172 (60%)	25 (9%)	0
Moderate (n=110)	27 (25%)	41 (37%)	40 (36%)	2 (2%)
Severe (n=8)	2 (25%)	0	4 (50%)	2 (25%)
Any MSI* (n=405)	2,465 (75%)	739 (22%)	98 (3%)	4 (0.1%)

*NB: WG data were missing for 30 people

Discussion

This all age population-based survey conducted in Fundong district in North-West Cameroon estimated a MSI prevalence of 11.6% (95% CI 10.1 – 13.3). The majority of MSI cases (70.4%) were classified as mild, 27.2% as moderate and 2.4% as severe. The prevalence of MSI increased dramatically with age, with 41.2% of cases of MSI found in people >50 years. Overall, 67% of MSI were due to acquired non-traumatic non-infective causes. The remainder of causes included trauma (14%), neurological (11%), infection (5%) and congenital (3%). Among participants ≥50 years, the cause of MSI was largely attributed to a broadly defined condition called degenerative joint disease (e.g. osteoarthritis). Nearly 40% of participants with MSI had never received medical care or rehabilitation for their condition.

The data from this survey provide useful information to assist planning of rehabilitation and other services for persons with MSI in Cameroon. For example, this study estimates that there are approximately of 35,000 people per million population in Cameroon with a moderate or severe MSI and 116,000 with any MSI. Throughout the county, approximately 800,000 people will have mild or worse degenerative joint conditions. The need for equipment (e.g. assistive devices) can also be estimated from this information and production and supply can be anticipated accordingly. Potential requirements for services such as rehabilitation and surgery can be similarly estimated. Combined with a situational analysis of existing capacity and resources, this can inform advocacy and planning of future rehabilitation and service provision. For example, the information collected in this survey on recommended interventions suggest that approximately 1,130,000 people in Cameroon could benefit from physiotherapy and 156,000 from surgery, yet there are currently 130 physiotherapists and physiotherapy assistants and 45 orthopaedic surgeons estimated in the country(14).

Comparison to previous studies

The overall prevalence of MSI in this study is double the 5.2% (95% CI 4.5–5.9) reported in Rwanda which used similar survey methods. While the estimated prevalence of moderate MSI (Cameroon 3.2%, Rwanda 2.4%) and severe (Cameroon 0.3%, Rwanda 0.4%), the number of participants assessed as having mild MSI was considerably higher in Cameroon (8.2% vs 2.4%). The reasons for this are unclear, but it may, in part, reflect the higher proportion of older adults (>50 years) included in the survey in Cameroon where the prevalence of mild MSI was particularly high. The assessment of mild MSI deserves further attention in future studies using this methodology. With regards to causes of MSI, our findings support those in Rwanda where a non-traumatic non-infective cause was the most common diagnostic category and the most common individual diagnosis was joint problems

(13% of MSI diagnoses).

The Global Burden of Disease Study estimates that in 2015 the most important contributors to global years lived with disability were musculoskeletal disorders (18.5% [16.4 – 20.9%]) (15). Lower back and neck pain were estimated in 2013 as the leading cause of years lived with disability in Cameroon (16). There are few other data in the region with which to compare our findings. Population prevalence of all disability was estimated as 6.2% (95% CI 5.2-7.2%) (17) through self-report in the North West Region of Cameroon. The Cameroon's Demographic and Health and Multiple Indicator Survey (2011) estimated that 5.4% of the population in Cameroon lives with a disability, with 6.6% in the North-West Region (18). However it is not clear what proportion of these estimates were physical disability. More comparable data from studies employing the same sampling methods and case definition are needed in different settings to strengthen the evidence on epidemiology of MSI in LMIC settings (7).

Older age and MSI

Our study highlights the high prevalence of MSI among older people. This finding supports studies of older person's health in Botswana and Malawi that demonstrate increased probability of musculoskeletal disease (19) and functional limitations (20) respectively. As the prevalence of musculoskeletal disorders increases with age, it follows that there will be a marked increase in requirements for health care and community support in the coming years. Despite having great need for rehabilitation services than younger age groups, evidence suggests that older people in sub-Saharan Africa use these services less frequently (21). Access to health and other services (for all ages) may be encouraged through community-based rehabilitation (CBR) programmes in rural communities. In addition, the development of programmes that serve populations at the district level (22), where needs can be assessed and resources identified, may improve access to preventative services and rehabilitation.

Treatment Gap

Medical or rehabilitation services were recommended for the majority of the people identified as having an MSI in this survey, 38% of people with MSI had not previously received any such services. These data, demonstrate a large treatment gap for MSI in Cameroon, similar to that of Rwanda (11). The challenge of improving access both to preventative services, aimed at preventing injury, and rehabilitation services is experienced globally (23-26). As the burden of MSI is predicted to increase as populations age, there is a need to recognise musculoskeletal conditions as a global public health priority. Innovative ways to fill this health

service gap are required. Examples such as mobile tools (27) or mentoring and supervision with train-the-trainer programmes (TBA) warrant further investigation.

Relationship between clinically assessed and self-reported MSI

The extent of overlap between the populations identified by clinical assessment and self-report varied considerably according to the severity of self-reported difficulties. The broader category of 'some or more difficulty' identified many people who did not have a moderate/severe clinical MSI, however sensitivity and specificity were within acceptable range with the inclusion of mild MSI. Using the narrower category 'a lot of difficulty' missed a considerable number of clinically confirmed cases. These two measurement approaches capture different aspects of disability (9) and a recent analysis has suggested that, where resources permit, using the two measures together in disability surveys may be helpful to identify the majority of people with disability (9). The need for RAM is highlighted as the self-reported measures alone at the level of 'some or more difficulty' underestimate MSI and do not provide information on clinical need.

Strengths and limitations

This was an all-age population based survey that used a standardised examination protocol to provide estimates of musculoskeletal impairment, with assessment by physiotherapists. Compact segment sampling reduced the likelihood of selection bias (28) and facilitated call back at households where people were unavailable. There were also study limitations. The study relied on simplified examination procedures that could be conducted in the field. Diagnostic tools were limited to history and clinical examination, which restricted the identification of aetiology that were reliant on complex investigations.

Conclusions

This paper contributes to the paucity of data on the epidemiology of MSI globally. The data from this survey provide useful information on planning services for persons with MSI in Cameroon.

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Appendix 2: Information Sheet for Participants in Cameroon and India

Participant information sheet 1: Household survey

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 unclear or if you would like more information.

What is the purpose of the study? We are doing a study to find out how many people with disabilities there are in Andhra Pradesh, India. We also want to know to what extent people with disabilities access services and what impact disability has on their daily lives. This information will be useful to help plan and improve the services that are available to and inclusive of people with disabilities.

What do we mean by "people with disabilities"? People with disabilities include those who have long-term physical, mental and intellectual or sensory impairments which may hinder their full and active participation in society

Why have I been chosen? We have randomly selected 51 areas in India and are inviting all people in these areas to take part in the study. You/your child(ren) have been chosen because your house is in one of these areas.

What is involved in the study? You/your child(ren) will have your eyesight, hearing and mobility checked by a doctor or nurse. We will also ask you some questions about your mental well-being and difficulties that you experience with different activities and daily life. If we find you have a problem with your eyes, ears, mobility, mental well-being or with different activities, 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. These include questions about your/your child(ren)'s life and health in general and the activities you/your child(ren) do. If you/your child(ren) do not have difficulties your eyes, ears, mobility or activities, you may still be randomly selected and invited to take part in this interview. The interview will take about 45 minutes.

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 problem with your eyes, ears, mobility or mental well-being and the survey teams finds you could benefit from a particular service that is available related to this, 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 to and inclusive of people with disabilities.

What are the risks? There are no risks of physical harm associated with this survey. The questions will take up a bit of your time – about 20minutes.

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(ren) agree to take part you are still free to withdraw at any time and without giving a reason.

If you have any further questions about that are not answered here or have require any further information or explanation please contact:

Local research lead: Mr. Obaid Rahman

Contact details: 9989268655
Indian Institute of Public Health,
ANV Arcade,
1 Amar Coop Society, Kavuri Hills, Madhapur
Hyderabad-500033;
Phone: 99126-44466.

Participant information sheet 2: 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 doing a study to find out how many people with disabilities there are India. We also want to know to what extent people with disabilities access services and what impact disability has on their daily lives. This information will be useful to help plan and improve the services that are available to and inclusive of people with disabilities.

What do we mean by "people with disabilities"? People with disabilities include those who have long-term physical, mental and intellectual or sensory impairments which may hinder their full and active participation in society

Why have I been chosen?

For a case: You/your child have been selected because of the difficulty with activities that you have.
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 will ask you some questions about difficulties that you/your child experience with different activities. We will also ask you some questions about your/your child's life and health in general including about services you use, education and work and also about the activities you do. The interview will take about 45 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. We are not from nor do we have any affiliation with the government.

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 to and inclusive of people with disabilities.

What are the risks? There are no risks of physical harm associated with this survey. The questions will take up a bit of your time – about 45minutes.

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.

If you have any further questions about that are not answered here or have require any further information or explanation please contact:

Local research lead: Mr. Obaid Rahman

Contact details: 9989268655
Indian Institute of Public Health,
ANV Arcade,
1 Amar Coop Society, Kavuri Hills, Madhapur
Hyderabad-500033;
Phone: 99126-44466.

Appendix 3: Questionnaires

Appendix 3 provides the Screening and Case-Control questionnaires used in the study. The screening questionnaire was completed using paper forms, whilst the Case-Control questionnaire was deployed on Google Nexus devices, using Open Data Kit software.

1. Interviewer No: ☐☐☐ 2. Date (Day/Month/Year): __/__/__

3. Cluster No: ☐☐ 4. House No: ☐☐

5. Subject Name: _____ 6. Subject ID No: ☐☐☐

7. Gender Male: O (1) 8. Age (years): ☐☐

Female: O (2) 9. Age (in months if <1 year): ☐☐

10. Screening Completion Matrix

	10.1 Screen Completed? Yes = 1 Unable to Complete = 2 Refused = 3	10.2 Screen Case = 1 Not Screen Case = 0	10.3 If screen positive, exam Completed? Yes = 1 Unable to Complete = 2 Refused = 3	10.4 If unable to complete screen or exam please give reason	10.5 Referral Needed Yes = 1 No = 0
A. WG Disability			N/A		N/A
B. PHQ9			N/A		
C. MSI Impairment					
D. Visual Impairment					
E. Hearing Impairment (OAE)			N/A		N/A
F. Hearing Imp (PTA) if OAE +ve					
G. Hearing Exam (if OAE and PTA screen positive)					

TO BE FILLED IN BY FIELD TEAM MEMBER RESPONSIBLE FOR CHECKING QUESTIONNAIRES FOR COMPLETION		CONFIRMED	
REMARKS:	_____	Case	O (1)
	Interviewer #	Control	O (2)
		Not eligible for Case/Control	O (3)

TO BE FILLED IN BY DATA ENTRY CLERK		
	Entry 1	Entry 2
INITIALS:		
DATE OF ENTRY:		
REMARKS:		

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Interviewer ID No ☐☐☐

A. Washington Group Questions for all participants AGED 2 to 17

I am now going to ask you some questions about certain everyday activities, and whether you have any difficulties in doing them. Please tell me if you do not understand question, and I will repeat it

Note to Interviewer: If respondent is aged 8-17 and being interviewed directly, replace "does [name]" with "do you" in questions.
Read all response options in full for each question asked

Children aged 2-17 years

1a) Does [name] wear glasses or contact lenses Yes O(1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
[if child wears glasses] 1b) Does [name] have difficulty seeing, when wearing his/her glassses?	O (1)	O (2)	O (3)	O (4)	O (5)
[if child does NOT wear glasses] 1c) Does [name] have difficulty seeing?	O (1)	O (2)	O (3)	O (4)	O (5)

Children aged 2-17 years

2a) Does [name] use a hearing aid? Yes O(1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
[if child uses a hearing aid] 2b) Does [name] have difficulty hearing, when using his/her hearing aid(s)?	O (1)	O (2)	O (3)	O (4)	O (5)
[if child does NOT use a hearing aid] 2c) Does [name] have difficulty hearing?	O (1)	O (2)	O (3)	O (4)	O (5)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
Children aged 2-17 years 3) Compared with children of the same age, does [name] have difficulty walking	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5- 17 years 4) Compared with children of the same age, does [name] have difficulty with self-care such as feeding or dressing him/herself?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2 -4 years 5a) Does [name] have difficulty understanding you?	O (1)	O (2)	O (3)	O (4)	O (5)
6a) Do you have difficulty understanding what your child wants?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5-17 years 5b) Compared with children of the same age and using [his/her] usual language, does [name] have difficulty understanding other people?	O (1)	O (2)	O (3)	O (4)	O (5)
6b)Compared with children of the same age and using [his/her] usual language, does [name] have difficulty being understood by other people?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-3 years 7a) Compared with children of the same age, does [name] have difficulty learning the names of common objects?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 3-17 years 7b) Compared with children of the same age, does [name] have difficulty learning to do new things?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5-17 years 8) Compared with children of the same age, does [name] have difficulty remembering things that they have learned?	O (1)	O (2)	O (3)	O (4)	O (5)

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐

	The same or Less	More	A lot more	Dont Know
Children aged 5-17 years 9) Compared with children of the same age, how much does [he /she] worry or feel sad?	O (1)	O (2)	O (3)	O (4)
Children aged 2-4 years children or adults?	O (1)	O (2)	O (3)	O (4)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
Children aged 5-17 years 10b) Compared with children of the same age, how much difficulty does [name] have controlling [his/her] behaviour?	O (1)	O (2)	O (3)	O (4)	O (5)
11) Compared with children of the same age, does [name] have difficulty completing a task?	O (1)	O (2)	O (3)	O (4)	O (5)
12) Compared with children of the same age, does [name] have difficulty accepting change to plans or routine?	O (1)	O (2)	O (3)	O (4)	O (5)
13) Does [name] have difficulty getting along with children of [his/her] age?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-5 years 14 a1) Compared with children of the same age, does [name] have difficulty playing with toys or household objects?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-12 years 14a2) Compared with children of the same age, does [name] have difficulty playing with other children?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 13-17 years 14b) Compared with children of the same age, does [name] have difficulty doing things with other children? (Include things that children usually do together.)	O (1)	O (2)	O (3)	O (4)	O (5)

15. Do you consider yourself [your child] to have a disability? O (1) Yes
O (0) No

Child SCREENS POSITIVE IF:
ANY QUESTION 1 to 8 SCORES "A lot More", "A lot of Difficulty" or "Cannot do at all"

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT

To Parent: Based on your/ your child's responses, it seems that your child may experience difficulties in doing certain things compared to other children his/her age, and we would like to ask some more questions about this.

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐☐

A. Washington Group Questions for all participants 18+

I am now going to ask you some questions about certain everyday activities, and whether you have any difficulties in doing them. Please tell me if you do not understand question, and I will repeat it

Note to Interviewer: Read all response options in full for each question asked

1a) Do you wear glasses or contact lenses Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
[If respondent wears glasses/contact lenses] 1b) Do you have difficulty seeing, even when wearing your glassses/contact lenses?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT wear glasses/contact lenses] 1c) Do you have difficulty seeing?	O (1)	O (2)	O (3)	O (4)	O (5)

2a) Do you use a hearing aid? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
[If respondent uses a hearing aid] 2b) Do you have difficulty hearing, even when using your hearing aid(s)?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT use a hearing aid] 2c) Do you have difficulty hearing?	O (1)	O (2)	O (3)	O (4)	O (5)

3a) Do you use any equipment or receive help for getting around? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
[If respondent uses equipment or receives help to get around] 3b) Do you have difficulty walking or climbing steps, even when using your equipment or with help?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT use equipment or receive help to get around] 3c) Do you have difficulty walking or climbing steps?	O (1)	O (2)	O (3)	O (4)	O (5)

4a) Do you use sign language? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
4b) Using your usual language, do you have difficulty communicating, for example understanding or being understood?	O (1)	O (2)	O (3)	O (4)	O (5)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Dont Know
5) Do you have difficulty remembering or concentrating?	O (1)	O (2)	O (3)	O (4)	O (5)
6) Do you have difficulty with self care, such as washing all over or dressing?	O (1)	O (2)	O (3)	O (4)	O (5)
7) Do you have difficulty raising a 2 litre bottle of water or soda from waist to eye level?	O (1)	O (2)	O (3)	O (4)	O (5)
8) 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	O (1)	O (2)	O (3)	O (4)	O (5)

	Daily	Weekly	Monthly	A few times a year	Never	Dont Know
9a) How often do you feel worried, nervous or anxious?	O (1)	O (2)	O (3)	O (4)	O (5)	O (6)

→ **If NEVER or DONT KNOW to 9a) Go to Q10**

Cluster no: ☐☐ Household no: ☐☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐☐

9b) Do you take medication for these feelings? Yes O (1) No O (0)

	A little	A lot	Somewhere between a little and a lot	Dont Know
9c) Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	O (1)	O (2)	O (3)	O (4)

	Daily	Weekly	Monthly	A few times a year	Never	Dont Know
10 a) How often do you feel depressed? Would you say	O (1)	O (2)	O (3)	O (4)	O (5)	O (6)

→ **If NEVER or DONT KNOW to 10a) Go to Q 11**

10b) Do you take medication for depression? Yes O (1) No O (0)

	A little	A lot	Somewhere between a little and a lot	Dont Know
10c) Thinking about the last time you felt depressed, how depressed did you feel?	O (1)	O (2)	O (3)	O (4)

	Never	Some Days	Most Days	Every Day	Dont Know
11a) In the past three months, how often did you have pain?	O (1)	O (2)	O (3)	O (4)	O (5)

→ **If NEVER or DONT KNOW to 11a) go to Q12**

	A little	A lot	Somewhere between a little and a lot	Dont Know
11b) Thinking about the last time you felt pain, how much pain did you have?	O (1)	O (2)	O (3)	O (4)

	Never	Some Days	Most Days	Every Day	Dont Know
12a) In the past three months, how often did you feel very tired or exhausted?	O (1)	O (2)	O (3)	O (4)	O (5)

→ **If NEVER to 12a) go to END OF SECTION**

	Some of the day	Most of the day	All of the day	Dont Know
12b) Thinking about the last time you felt very tired or exhausted, how long did it last?	O (1)	O (2)	O (3)	O (4)

	A little	A lot	Somewhere between a little and a lot	Dont Know
12c) Thinking about the last time you felt this way, how would you describe the level of tiredness?	O (1)	O (2)	O (3)	O (4)

Participant SCREENS POSITIVE If:Any Question 1 to 8 scores "A lot", "A lot of Difficulty" or "Cannot do at all"

15. Do you consider yourself [your child] to have a disability? O (1) Yes O (0) No

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

To Participant: Based on your responses, it seems that you may experience difficulties in doing certain things compared to other people, and we would like to ask some more questions about this.

5

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐☐

B. PHQ-9 Questions for all participants >17

I am now going to ask you a few questions about how you have been feeling recently. Please tell me if you do not understand a question, and I will repeat it

Over the last two weeks, how often have you been bothered by any of the following problems?

	Not at all	Several Days	More than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	O (0)	O (1)	O (2)	O (3)
2. Feeling down, depressed, or hopeless	O (0)	O (1)	O (2)	O (3)
3. Feeling tired or having little energy	O (0)	O (1)	O (2)	O (3)

→ **If no responses in SHADED AREA go to NEXT SECTION**

4. Trouble falling/staying asleep, sleeping too much	O (0)	O (1)	O (2)	O (3)
5. Poor appetite or overeating	O (0)	O (1)	O (2)	O (3)
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	O (0)	O (1)	O (2)	O (3)
7.Trouble concentrating on things, such as reading the newspaper or watching television	O (0)	O (1)	O (2)	O (3)
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	O (0)	O (1)	O (2)	O (3)
9.Thoughts that you would be better off dead or of hurting yourself in some way	O (0)	O (1)	O (2)	O (3)

Column Totals: _____ + _____ + _____

Total Score (Add Totals together): _____

Participant SCREENS POSITIVE if: Total score greater than 19 and includes at least one answer in the shaded area

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

C. RAPID ASSESSMENT OF MUSCULOSKELETAL IMPAIRMENT

A. GENERAL INFORMATION

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

Examination status: Examined: O (1)
Unable to examine: O (2) Reason: _____
Refused: O (3)

B. SCREEN FOR MUSCULOSKELETAL IMPAIRMENT

I am going to ask you now a few questions about your physical health and abilities.

1. Who is responding?

Screen by eligible person: O (1)
Screen by proxy: O (0)

2. Use this prefix for 5 and under (by proxy): Compared to other children

	Yes	No
1. Is any part of your body missing or misshapen?:	O (1)	O (0)
2. Do you have any difficulty using your arms?:	O (1)	O (0)
3. Do you have any difficulty using your legs?:	O (1)	O (0)
4. Do you have any difficulty using any other part of your body?:	O (1)	O (0)
5. Do you need a mobility aid or prosthesis?:	O (1)	O (0)
6. Do you have convulsions, involuntary movement, rigidity or loss of consciousness?:	O (1)	O (0)

3. Duration

	Yes	No
1. Has it lasted>1m?	O (1)	O (0)
2. Is it permanent?	O (1)	O (0)

Examine Participant if: Answer to at least one Q.1-6 is Yes and Answer to at least one "Duration" question is Yes

MSI Exam Needed Yes O (1) No O (0)

C. OBSERVATION OF ACTIVITIES

		Yes	No
I. Position	Squat/sit bending knees:	O (1)	O (0)
	Stand up straight on natural legs:	O (1)	O (0)
	Hold arms straight above head, fingers straight:	O (1)	O (0)
II. Mobility	Walk along the 11 metre rope:	O (1)	O (0)
	Do it in less than 10 secs:	O (1)	O (0)
	Do it without limping:	O (1)	O (0)
III. Right hand function	Touch Nose:	O (1)	O (0)
	Pick up coin and put in cup:	O (1)	O (0)
	Tip coin into bowl:	O (1)	O (0)
IV. Left hand function	Touch Nose:	O (1)	O (0)
	Pick up coin and put in cup:	O (1)	O (0)
	Tip coin into bowl:	O (1)	O (0)

D. SEIZURE HISTORY

1 Have you ever had a seizure?
No history of seizure: O (0)
History of seizure: O (1)

2 Have you had three or more seizures in the past year?
3 or more seizures No O (0)
Yes O (1)
Not applicable (never had seizure): O (3)

3 Number of episodes in last year:
0: O (1)
1-2: O (2)
3-10: O (3)
>10: O (4)
Not applicable (never had seizure): O (5)

4 Type of seizure (tick one only)
Absences: O (1)
Convulsions: O (2)
Not applicable (never had seizure): O (3)

E. DURATION AND CONSANGUINITY

1 Age at impairment:
Since birth: O (1)
after birth-1 year: O (2)
1-5 years O (3)
6-15 years: O (4)
16-39 years: O (5)
>40 years: O (6)
Not applicable (No impairment:) O (7)

	No	Yes
2 Consanguinity:	O (0)	O (1)

F. AETIOLOGY

Tick one only for each impairment

	Impairment no: 1	2
Family history:	O	O (1)
Congenital but no family history:	O	O (2)
Perinatal hypoxia:	O	O (3)
Trauma — RTA:	O	O (4)
Trauma — Civil violence:	O	O (5)
Trauma — Domestic violence:	O	O (6)
Trauma — Deliberate self harm:	O	O (7)
Trauma — Other inc accidents:	O	O (8)
Trauma — Specify.....		
Developmental / Nutritional:	O	O (9)
Infection:	O	O (10)
Neoplasm:	O	O (11)
Iatrogenic:	O	O (12)
Traditional	O	O (13)
Unknown:	O	O (14)
Other:	O	O (15)
Specify.....		
Not applicable (No impairment:)	O	O (16)

G. STRUCTURE AND FUNCTION

Region	Structure affected Yes	Structure affected No	Laterality Left = 1 Right = 2 Both = 3	Nature of change (see codes below)	Magnitude (see codes below)
1. Head and Neck	O (1)	O (0)			
2. Shoulder region	O (1)	O (0)			
3. Upper arm	O (1)	O (0)			
4. Elbow Joint	O (1)	O (0)			
5. Forearm	O (1)	O (0)			
6. Wrist Joint	O (1)	O (0)			
7. Hand	O (1)	O (0)			
8. Hand/Finger Joints	O (1)	O (0)			
9. Whole arm	O (1)	O (0)			
10. Pelvis	O (1)	O (0)			
11. Hip joint	O (1)	O (0)			
12. Thigh	O (1)	O (0)			

Region	Structure affected Yes	Structure affected No	Laterality Left = 1 Right = 2 Both = 3	Nature of change (see codes below)	Magnitude (see codes below)
13. Knee Joint	O (1)	O (0)			
14. Lower leg	O (1)	O (0)			
15. Ankle Joint	O (1)	O (0)			
16. Foot	O (1)	O (0)			
17. Foot/Toe Joints	O (1)	O (0)			
18. Whole Leg	O (1)	O (0)			
19. Trunk	O (1)	O (0)			
20. C-spine	O (1)	O (0)			
21. T-spine	O (1)	O (0)			
22. L-spine	O (1)	O (0)			
23. Whole body	O (1)	O (0)			

Nature of Change Codes: No change in structure = 0; Total absence = 1; Partial absence = 2; Additional Part = 3; Aberrant dimensions = 4; Discontinuity = 5; Deviating Position = 6; Qualitative changes = 7; Not Specified = 8; Not applicable = 9

Magnitude of Function: No impairment = 0; Mild Impairment = 1; Moderate Impairment = 2; Severe Impairment = 3; Complete Impairment = 4

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

G. DIAGNOSTIC CASE CONFIRMATION

Case: O (1)
Not case: O (0)

H. CASE Type

H1 Type Case
MSI (1)
Epilepsy (2)

H2 MSI Case severity:
Mild O (1)
Moderate: O (2)
Severe: O (3)

I. DIAGNOSIS DECISION ALGORITHM

Is it congenital? Yes → a. CONGENITAL/GENETIC
No → Is it due to an infection? Yes → b. INFECTIVE
No → Is it due to trauma? Yes → c. ACQUIRED TRAUMA
No → Is it neurological in cause or nature? Yes → d. NEUROLOGICAL
No → e. ACQUIRED NON TRAUMATIC

a. CONGENITAL/GENETIC

UPPER LIMB
- O (01) Polydactyly
- O (02) Syndactyly
- O (03) Other congenital hand deformity
- O (04) Other congenital absence of all or part of upper limb
- O (05) Other congenital abnormality of upper limb

LOWER LIMB
- O (10) Developmental dysplasia of hip
- O (11) Proximal focal femoral deficiency
- O (12) Congenital absence of all or part of tibia
- O (13) Congenital absence of all or part of fibula
- O (14) Other congenital absence of all or part of lower limb
- O (15) Club foot
- O (16) Other congenital abnormality of lower limb

UPPER AND LOWER LIMB
- O (20) Amniotic bands
- O (21) Arthrogryphosis

SPINE
- O (30) Congenital deformity of cervical spine
- O (31) Congenital deformity of thoracolumbar spine

HEAD AND NECK
- O (40) Cleft lip
- O (41) Cleft lip and palate
- O (42) Other congenital deformity of head or face

GENERAL
- O (50) Multiple congenital abnormalities
- O (51) Sickle cell disease
- O (52) Osteogenesis imperfecta
- O (53) Haemophilia
- O (54) Muscular Dystrophy

b. INFECTIVE
- O (01) Joint Infection
- O (02) Bone infection limb
- O (03) Bone infection spine
- O (03) Skin/soft tissue infection/wound

c. ACQUIRED TRAUMA
- O (01) Burn contracture
- O (10) Fracture non unioin
- O (11) Fracture malunion
- O (12) Spinal injury
- O (13) Head injury
- O (20) Recurrent/chronic dislocation
- O (21) Post traumatic joint stiffness
- O (30) Tendon problem
- O (31) Muscle problem
- O (32) Peripheral nerve problem
- O (40) Amputation
- O (50) Other Trauma

d. NEUROLOGICAL
- O (01) Epilepsy
- O (02) Leprosy
- O (03) Developmental delay
- O (04) Cerebral palsy - spastic
- O (05) Cerebral palsy - other
- O (06) Paraplegia
- O (07) Hemiplegia
- O (08) Quadriplegia
- O (09) Facial weakness
- O (10) Peripheral nerve palsy
- O (11) Polio
- O (12) Other neurological

e. ACQUIRED NON TRAUMATIC
- O (01) Degenerative joint disease
- O (02) Non infective non traumatic joint disease
- O (03) Bow legs
- O (04) Knock knees
- O (05) Other joint deformity
- O (11) Bone tumour (benign or malignant)
- O (21) Skin/Soft tissue tumour
- O (40) Spinal deformity-kyphosis
- O (41) Spinal deformity-lordosis
- O (42) Spinal deformity-scoliosis
- O (43) Spinal pain limiting function
- O (44) TB spine/spine infection
- O (50) Limb pain limiting function
- O (60) Lymphoedema
- O (70) Other acquired non traumatic

f. NO DIAGNOSIS
- O (01) No Diagnosis

J. CASE DIAGNOSIS CODE

Diagnosis 1 ___ _____ _____ ☐☐☐
Diagnosis 2 _____ _____ ☐☐☐

K. TREATMENT INFORMATION

	Previous Yes	Previous No	Needed Yes	Needed No
1. None:	O (1)	O (0)	O (1)	O (0)
2. Medication:	O (1)	O (0)	O (1)	O (0)
3. Plaster/Splintage:	O (1)	O (0)	O (1)	O (0)
4.Physiotherapy	O (1)	O (0)	O (1)	O (0)
5. Special Seating:	O (1)	O (0)	O (1)	O (0)
6. Mobility aid:	O (1)	O (0)	O (1)	O (0)
7. Tricycle:	O (1)	O (0)	O (1)	O (0)
8.Appliance:	O (1)	O (0)	O (1)	O (0)
9. Orthosis	O (1)	O (0)	O (1)	O (0)
10. Prosthesis:	O (1)	O (0)	O (1)	O (0)
11.Wheelchair:	O (1)	O (0)	O (1)	O (0)
12.Surgery:	O (1)	O (0)	O (1)	O (0)
13. Permanent care:	O (1)	O (0)	O (1)	O (0)
14. Traditional medicine:	O (1)	O (0)	O (1)	O (0)
15 Other:	O (1)	O (0)	O (1)	O (0)
Specify:				

L. WHY I HAVE NOT HAD (FURTHER) TREATMENT

- Unaware of Impairment O (1)
- Believes it to be a curse O (2)
- Services not available or very far O (3)
- No / delayed information about services O (4)
- Cannot afford treatment O (5)
- No one to accompany O (6)
- No time available / other priorities O (7)
- Old age and need not felt O (8)
- Adequate function / need not felt O (9)
- Fear of treatment O (10)
- Not applicable O (11)

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

D. VISUAL IMPAIRMENT

A. GENERAL INFORMATION

Examination status: Examined: O (1)
Unable to examine: O (2) Reason:
Refused: O (3)

Screen Case: O (1)
Not Screen case: O (0)

Always ask: "Did you ever have any problems with your eyes?"

B. VISION SCREEN

Using distance glasses: Yes O (1) No O (0)
Using reading glasses: Yes O (1) No O (0)

i)AGE 5+ YEARS

Presenting

	Right eye	Left eye	
Can see 6/18	O (1)	O (1)	
Cannot see 6/18 but can see 6/60	O (2)	O (2)	
Cannot see 6/60 but can see 3/60	O (3)	O (3)	CASE
Cannot see 3/60 but can see 1/60	O (4)	O (4)	
Light perception (PL+)	O (5)	O (5)	
No light perception (PL-)	O (6)	O (6)	

With Pinhole

	Right eye	Left eye
Can see 6/18	O (1)	O (1)
Cannot see 6/18 but can see 6/60	O (2)	O (2)
Cannot see 6/60 but can see 3/60	O (3)	O (3)
Cannot see 3/60 but can see 1/60	O (4)	O (4)
Light perception (PL+)	O (5)	O (5)
No light perception (PL-)	O (6)	O (6)

ii)AGE 0-2 YEARS

Can the child look at and follow a moving object? Yes: O (1) No: O (0) Unable to examine O (2)

iii)AGE 3-4 YEARS

Can child count/copy fingers from 6 meters with both eyes open? Yes: O (1) No: O (0) Unable to examine O (2)

E. WHY CATARACT OPERATION WAS NOT DONE

(Mark up to 2 responses, if VA<6/18, not improving with pinhole, with visually impairing lens opacity in one or both eyes)

- Need not felt O (1)
- Fear of surgery or poor result O (2)
- Cannot afford operation O (3)
- Treatment denied by provider O (4)
- Unaware treatment is possible O (5)
- No one to accompany O (6)
- No time available / other priorities O (7)
- Told to wait for cataract to mature O (8)

C. LENS EXAMINATION

	Right eye	Left eye
Normal lens / minimal lens opacity:	O (1)	O (1)
Obvious lens opacity:	O (2)	O (2)
Lens absent (aphakia):	O (3)	O (3)
Pseudophakia without PCO:	O (4)	O (4)
Pseudophakia with PCO:	O (5)	O (5)
No view of lens:	O (6)	O (6)

D. MAIN CAUSE OF PRESENTING VA<6/18

(Mark only one cause for each eye)

	Right eye	Left eye	Principal cause in person
Refractive error:	O (1)	O (1)	O (1)
Cataract, untreated	O (2)	O (2)	O (2)
Aphakia, uncorrected:	O (3)	O (3)	O (3)
Surgical complications:	O (4)	O (4)	O (4)
Trachoma:	O (5)	O (5)	O (5)
Phthisis/disorganised/removed:	O (6)	O (6)	O (6)
Other corneal scar/opacity:	O (7)	O (7)	O (7)
Globe abnormality:	O (8)	O (8)	O (8)
Cortical blindness:	O (9)	O (9)	O (9)
Dilate pupil			
Glaucoma:	O (10)	O (10)	O (10)
Diabetic retinopathy:	O (11)	O (11)	O (11)
ARMD:	O (12)	O (12)	O (12)
Onchocerciasis:	O (13)	O (13)	O (13)
Other post. segment / CNS:	O (14)	O (14)	O (14)
Not examined (can see 6/18)	O (15)	O (15)	O (15)

F. DETAILS ABOUT CATARACT OPERATION

	Right eye	Left eye
Age at operation (years)	☐☐	☐☐
Place of operation		
Government hospital	O (1)	O (1)
Voluntary / charitable hospital	O (2)	O (2)
Private hospital	O (3)	O (3)
Eye camp / improvised setting	O (4)	O (4)
Traditional setting	O (5)	O (5)
Type of surgery		
Non IOL	O (1)	O (1)
IOL implant	O (2)	O (2)
Couching	O (3)	O (3)
Cost of surgery		
Totally free	O (1)	O (1)
Partially free	O (2)	O (2)
Fully paid	O (3)	O (3)
Cause of VA<6/18 after cataract surgery		
Ocular comorbidity (Selection)	O (1)	O (1)
Operative complications (Surgery)	O (2)	O (2)
Refractive error (Spectacles)	O (3)	O (3)
Longterm complications (Sequelae)	O (4)	O (4)
Does not apply - can see 6/18	O (5)	O (5)
Are you satisfied with results of cataract surgery?		
Very satisfied	O (1)	O (1)
Partially satisfied	O (2)	O (2)
Indifferent	O (3)	O (3)
Partially dissatisfied	O (4)	O (4)
Very dissatisfied	O (5)	O (5)

E. OAE SCREEN FOR HEARING IMPAIRMENT

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

1. OAE Equipt No. ☐☐

2

RIGHT EAR	Pass	Fail	Not done - discharging ear	Not done - other
	O (1)	O (2)	O (3)	O (4)

LEFT EAR	Pass	Fail	Not done - discharging ear	Not done - other
	O (1)	O (2)	O (3)	O (4)

3 State reason if "not done - other": _____

Pure Tone Audiometry (PTA) needed if Participant FAILS OAE in BOTH EARS or if OAE can not be done/read for any reason

Pure Tone Audiometry Test Needed Yes O (1) No (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

F. PTA FOR HEARING IMPAIRMENT IF BOTH EARS FAIL OAE

II. AUDIOMETRY **If aged 4+ and OAE fails in BOTH ears or can not be done**

1. Ambient Noise ☐☐.☐ dBA 2. PTA Equipment No. ☐☐

2. Hearing Thresholds

	Right (dBHL)		Left (dBHL)
a.	☐☐	1 KHz	☐☐
b.	☐☐	2 KHz	☐☐
c.	☐☐	4 KHz	☐☐
d.	☐☐	0.5 KHz	☐☐
e.	☐☐	1 KHz	☐☐
f. Average score a-d	☐☐		☐☐

Note: If 1KHz (e.) score not within +/- 5dbHL of 1KHz (a.) score repeat PTA screen

Partipant SCREENS POSITIVE if Average score (f) is >35dBa for 0-17 year olds or >40dBa for 18+ in BOTH ears

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

G. WHO/PBD Ear and Hearing Disorders Examination Form

A. GENERAL INFORMATION

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

B. BASIC EAR ASSESSMENT FOR HEARING IMPAIRMENT CASES ONLY

	Right			Left		
	No	Yes	Not Asked	No	Yes	Not Asked
I. Ear Pain	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
II. Auricle	N	M	N/E	N	M	N/E
	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)

N = Normal; M= Malformation; N/E = Not Examined

III. External Canal

	N	Y	N/E	N	Y	N/E
1. Normal	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
2. Inflammation	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
3. Wax	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
4. Foreign Body	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
5. Otorrhoea	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
6. Fungi	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)

N= No; Y= Yes; N/E = Not Examined

IV. Ear Drum	Right				Left			
	N	Y	N/E	U	N	Y	N/E	U
1. Perforation	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
2. Dullness or Retraction	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
3. Red and Bulging	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
4. Normal	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)

N= No; Y= Yes; N/E = Not Examined; U= Unsure

V. Middle Ear								
	N	Y	N/E	U	N	Y	N/E	U
1. Normal	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
2. Otorrhoea	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)

VI. Others	N	Y	N/E	U	N	Y	N/E	U
	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)

1. If Yes, Specify _____

VII. Additional Information

1. How Long has the subject had difficulty hearing?

Since Infancy/childhood (0-4y) O (1)
Somce adulthood (15-59y) O (2)
Since old age (60y+) O (3)
Uncertain O (4)
No Difficulty O (5)
Not Asked O (6)

2. Does any relative of the subject have difficulty hearing?

No O (0)
Yes O (1) → 3. If yes, specify: Brother or Sister O (1); Child of Subject O (2); Parent of Subject O (3)
Uncertain O (3)
Not Asked O (4)

D. CAUSE OF EAR DISEASE AND/OR HEARING IMPAIRMENT

Please tick all that apply

	Right ear	Left ear
Normal ear AND normal hearing	O (1)	O (1)
I. Ear Disease		
1. Wax	O (2)	O (2)
2. Foreign Body	O (3)	O (3)
3. Otitis Externa...	O (4)	O (4)
4. Acute Otitis Media	O (5)	O (5)
5. Chronic Suppurative Otitis Media	O (6)	O (6)
6. Serous Otitis media (with effusion)	O (7)	O (7)
7. Dry perforation of Tympanic Membrane	O (8)	O (8)
II. Infectious Diseases	O (9)	O (9)
Specify _____		
III. Genetic Conditions	O (10)	O (10)
Specify _____		
IV. Non-Infectious Conditions	O (11)	O (11)
Specify _____		
V. Underermined Cause	O (12)	O (12)
Specify _____		
VI. Other	O (13)	O (13)
Specify _____		

E. ACTION NEEDED

I. No Action Needed O (1)

II. Action Needed	N	Y	U
1. Medication	O (0)	O (1)	O (2)
2. Hearing Aid	O (0)	O (1)	O (2)
3. Language/Speech Rehabilitation	O (0)	O (1)	O (2)
4. Special Needs Education	O (0)	O (1)	O (2)
5. Vocational Training	O (0)	O (1)	O (2)
6. Surgery Referral	O (0)	O (1)	O (2)
Urgent	O (0)	O (1)	O (2)
Non Urgent	O (0)	O (1)	O (2)

N= No; Y= Yes; U=Unsure

	N	Y	U
7. Others	O (0)	O (1)	O (3)

Specify _____

III. Any Additional Examiner Remarks:

_____
_____
_____
_____

CAMEROON DISABILITY STUDY 2013 - Case Control Questionnaire

COVER SHEET

1 Cluster No. ☐☐ 2 House No. ☐☐ 3 Subject ID No. ☐☐☐

4 Subject Name: _____

5 Interviewer No. ☐☐☐ 6 Date (Day/Month/Year): __ __ / __ __ / __ __

7 Language of Interview:
- 1 = English
- 2 = Pidgeon

8 Is study subject a case or control?
- 1 = Case (Person with a disability)
- 2 = Control

9 What is the study subject's age (years)? ☐

10 What is the study subject's gender (observe)
- 1 = male
- 2 = female

11 Is the study subject the head of the household?
- 0 = No
- 1 = Yes

12 Is there another case in this household who has already been interviewed?
- 0 = No if NO, GO TO Q14
- 1 = Yes

13 If yes, what is that person's ID no ☐☐

14 Person interviewed:
- 1 = Direct interview with case/control
- 2 = Interview with proxy only
- 3 = Interview with proxy and case/control together

ID of proxy respondant: ☐
ID of proxy respondant: ☐

A SOCIO-ECONOMIC QUESTIONS (OLDEST CASE PER HOUSEHOLD)

I am now going to ask you a few questions about your household

Note to Interviewer: If there is more than one case in the household, this section should be asked to thefirst case ONLY

1 What is the major construction material of the external walls?
- 1 = Brick
- 2 = Concrete
- 3 = Unbaked brick, adobe
- 4 = Wood, logs
- 5 = Iron/Tin/zinc sheeting
- 6 = Mud
- 7 = Bamboo
- 8 = Canvas, felt
- 9 = Other, Specify: _____

2 What is the major material of the roof?
- 1 = Concrete
- 2 = Tiles/shingles
- 3 = Asbestos sheets
- 4 = Metal sheets
- 5 = Wood
- 6 = Unbaked bricks
- 7 = Thatch
- 8 = Other, Specify: _____

3 What is the primary material of the floor?
- 1 = Parquet/linoleum
- 2 = Painted wood
- 3 = Tile
- 4 = Concrete
- 6 = Clay/earthen floor
- 7 = Other, Specify: _____

4 How many rooms are there in your household (excluding bathrooms, kitchens, balconies and corridors)? ☐☐

5 What is the main source of lighting in your household?
- 1 = Mains power
- 2 = Generator/batery/inverter
- 3 = Kerosene/oil/petrol lamps
- 4 = Candles
- 5 = No lighting
- 6 = Other, specify: _____

6 Does any member of your household own the following : (in working order)

		0 = No	1 = Yes			0 = No	1 = Yes
a	Radio/HiFi/Stereo	0	1	j	Washing machine	0	1
b	TV/VCR/DVD	0	1	k	Sewing machine	0	1
c	Fridge/Freezer	0	1	l	Air conditioner	0	1
d	Mobile phone	0	1	m	Bicycle	0	1
e	Cupboard	0	1	n	Stove with gas	0	1
f	Sofa set/armchair	0	1	o	Stove with electric	0	1
g	Table	0	1	p	Computer	0	1
h	Motor vehicle incl cars	0	1	q	Kerosene Gas Stove	0	1
i	Motorbike	0	1				

B. Water and Sanitation

NB - questions 1,2, 7, 8 and 9 should only be answered once for each household, so if there are more than one cases per household, should only be filled in for thefirst case interviewed

1 What kind of toilet facilities do members of your household usually use
1 = Flush toilet
2 = Traditional latrine
3 =Ventilation improved pit latrine
4 = Bowl/Bucket
6 = No toilet
5 = Other, Specify:

2 Do you share this facility with other households?
1 = Used only by your household
2= Shared with other households
3 = Public/ Communal/ Community Latrine

3 **CASES ONLY (Qs 3-6)**
Do you use the same toilet facility as other members of your household?
0 = No
1 = Yes If YES, go to Q6

4 Why do you use a different toilet facility from other members of your household (main reason)
1 = It would be physically impossible
2 = I'm not allowed/others would not like it
3 = I might face verbal or physical abuse
4 = I would be embarrased
5 = Other (specify) _____

5 What kind of toilet facility do you usually use?
1 = Flush toilet
2 = Traditional latrine
3 =Ventilation improved pit latrine
4 = Bowl/Bucket
6 = No toilet
5 = Other, Specify:

6 Are you usually able to use the toilet facility without you or your clothes coming into contact with feaces
0 = No
1 = Yes

ALL RESPONDENTS

7 What is the main souce of drinking water fc members of your household?
1 = Private pipeline
2 = Private well
3 = Public taps/standpipe
4 = Public well
5 = Neighbours
6 = Water vendor
7 = Spring
8 = River/stream/lake
9 = Rainwater
10 = Other, specify:

8 How long does it take to go there, get water and come back? [ ][ ][ ] minutes

9 Where do members of your household normally bath?
1 = Surface water (eg. Pond, river, sea)
2= Pump or standpipe stored outside compound
3= Piped or stored water inside the house or compound

CASES ONLY (Q10-13)

10 Do you collect water for drinking?
0 = No If NO, go to Q15
1 = Yes

11 Do you collect drinking water from the same source as other members of your household?
0 = No
1 = Yes

12 How long does it take to go there, get water and come back? [ ][ ][ ] minutes

13 From what source do you usually collect drinking water?
1 = Private pipeline
2 = Private well
3 = Public taps/standpipe
4 = Public well
5 = Neighbours
6 = Water vendor
7 = Spring
8 = River/stream/lake
9 = Rainwater
10 = Other, specify:

14 Is this the same source as the water you use for bathing?
0= No
1 = Yes

15 Could you collect water from the same source used by other members of your household?
0 = No
1 = Yes If YES, go to Q16

16 If no, why not?
1 = It would be physically impossible
2 = I'm not allowed/others would not like it
3 = I might face verbal or physical abuse
4 = I would be embarrased
5 = Other (specify)

17 Are you able to access drinking water at home without assistance?
0 = No
1 = Yes

18 **ALL RESPONDENTS**

Have you had diarrhoea in the past four weeks?
0 = No
1 = Yes

C. Marital status, literacy and education (PARTICIPANTS 18 YEARS AND ABOVE ONLY)

Now I would like to ask you a few questions about your living status and education

1 What is your marital status?	1 = Married or living together 2 = Divorced/seperated 3 = Widowed 4 = Never married/living together
2 Can you read well, a little or not at all?	1 = Well 2 = A little 3 = Not at all
3 Have you ever attended School	0 = No If NO, go t o Q6 1 = Yes
4 What is the highest level of education you completed	1 = Primary 2 = Secondary 3 = High School 4 = University
5 What was the highest grade that you completed?	☐ Go to Q7
6 What is the main reason why you did not receive formal education?	1 = absence of school 2 = Lack of money 3 = Needed to work 5 = Education not very useful 6 = Being disabled was refused 7 = Don't like school 8 = Too much household work 9 = Family does not allow 10 = No transport 11 = Other - specify

Ask this question about head of the household (if he/she is NOT the study subject)

7 What is the highest level of education [name] completed	1 = Primary 2 = Secondary 3 = High School 4 = University 5= No education
8 What was the highest grade that [name] completed?	☐
9 Can [name] read well, a little or not at all?	1 = Well 2 = A little 3 = Not at all

D. Education questions (CASES/CONTROLS AGED 17 YEARS AND BELOW ONLY)

Note to interviewer: If answered by proxy replace "are you" with "is [name]"

1 Are you currently enrolled in school?	0 = No If NO, go to Q7 1 = Yes
2 Are you enrolled in the same grade as other children your age?	1 = Yes 2= No, lower grade than other children my age 3= No, a higher grade than other children my age
3 Is the school you are in a mainstream/regular school or special school?	1 = Mainstream/regular 2 = Special school 3 = Integrated 4 Mainstream with special/extra classes
4 In the last month of school, how many days did you miss?	☐☐ days
5 Have you ever repeated a grade at school	0 = No If NO, go to Q11 1 = Yes
6 If yes, how many times have you repeated a grade at school	☐ If NO, go to Q11
7 If not currently enrolled, have you ever attended school?	0 = No If NO, go to Q10 1 = Yes
8 What is the highest level of education you completed	1 = Primary 2 = Secondary 3 = High School 4 = University
9 What was the highest grade that you completed?	☐
10 If you have never attended/are currently not attending school, what is the main reason?	1 = Not enough money 2 = Lack of interest to go to school 3 = Lack of school nearby 4 = Nearby school not accessible 5 = Illness (<1 month) 6 = Illness (> 1 month) 7 =Attendance refused by school 8 = Negative attitudes of other students 9 = Negative attitudes of teachers 10 = Lack of accessible resources to assist child 11 = Child works 12= Other, Specifiy:_____

Q11 CHILDREN CURRENTLY ENROLLED (CASES AND CONTROLS) IN SCHOOL (Yes to QD1) ONLY

11 If you currently attend school, how often do the following situations happen to you?

	Always	Sometimes	Never	Dont Know
A. If you have a problem at school there are teachers willing to help you	1	2	3	4
B. If you have a problem at school there are friends to help you	1	2	3	4
C. If your friends have a problem at school they come to you for help	1	2	3	4
D. You have friends that you play with at breaktimes	1	2	3	4
E. Your friends look up to you as a leader	1	2	3	4
F. Children hit, hurt or say nasty things to you	1	2	3	4
G. Teachers hit, hurt or say nasty things to you	1	2	3	4
H. You are included in lessons and school activities	1	2	3	4
I. Your school has the right materials to help you learn	1	2	3	4

Q12 - 18 FOR CASES CURRENTLY ENROLLED IN SCHOOL ONLY

12 I want to know more about your school and whether it is adapted for your needs

	Yes	No	Not Applicable
A. Do you get extra time to complete work or tests	1	2	3
B. Does the teacher teach in a way that makes it easy for	1	2	3
C. Do you get extra lessons?	1	2	3
D. Are teaching aids adapted for you eg. Are pictures used	1	2	3
E. Does another person in the classroom help you?	1	2	3
F. Is the class environment adapted for you eg. Lighting, or	1	2	3
G. Are communication devices used to help you eg.	1	2	3
H. Is text put in Braille or large font, or audio taped?	1	2	3
I. Are hearing or visual aids used	1	2	3
J. Does someone use sign language with you?	1	2	3
K. Is the playground accessible?	1	2	3
L. Is there an accessible toilet?	1	2	3

13 At school are you able to use the same toilet facility as other pupils?
0 = No
1 = Yes If YES, go to Q14

14 If no, what is the main reason why not?
1 = It would be physically impossible
2= I could not use it without getting myself or my clothes soiled
3 = I'm not allowed/others would not like it
4 = I might face verbal or physical abuse
5 = I would be embarrased
6 = Other (specify) _____

15 At school are you able to access drinking water from the same source as other pupils?
0 = No
1 = Yes If YES, go to Q17

16 If no, what is the main reason why not?
1 = It would be physically impossible
2 = I'm not allowed/others would not like it
3 = I might face verbal or physical abuse
4 = I would be embarrased
5 = Other (specify) _____

17 At school are you able to wash your hands at the same place as other pupils?
0 = No
1 = Yes If YES, GO TO NEXT SECTION

18 If no, what is the main reason why not?
1 = It would be physically impossible
2 = I'm not allowed/others would not like it
3 = I might face verbal or physical abuse
4 = I would be embarrased
5 = Other (specify)

E Livelihood questions (CASES/CONTROLS AGED 18 YEARS AND ABOVE ONLY)

I would now like to ask you some questions about work

1 Other than domestic work in the household
Have you done any work in the last seven days?
0 = No
1 = Yes If YES, Go to Q4

2 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?
0 = No
1 = Yes If YES, Go to Q4

3 Have you done any work in the last 12 months?
0 = No If NO, go to Q8
1 = Yes

4 What is your occupation, that is, what kind of work do you mainly do?
Code ☐☐

5 In this work do you :
work on your own/household's business (e.g. Shopkeeper, taxi driver, carpenter, barber) or work for someone who is not a member of your household (e.g. enterprise, company, government/other individual) or work on farm owned/rented by yourself or household member
1 = own/household business
2 = non-household member
3 = farm owned/rented by household

6 Do you usually work throughout the year, or do you work seasonally, or only once in a while?
1= Throughout the year
2 = Seasonally/part of the year
3 = Once in a while

7 Are you paid in cash or kind for this work or are you not paid at all?
1 = Cash only
2 = Cash and kind
3 = In kind only
4 = Not paid
Go to Q9

8 If not working, what is the main reason ?
1= Student
2= Childcare/duties/work inside the house
3= Too old / retired
4= Incapable of working, physically
5= Incapable of working, mentally
6= Nobody would give me a job because I am disabled
7= Long illness (>1 month)
8= I am looking for my first job
9= No jobs opportunities in the area
10= Quit/suspended from job
11= Other (please specify): .....

9 Do you receive any of the following benefits

	Yes	No
A. Social security grar	1	2
B. Disability grant	1	2
C. Pension	1	2
D.Family Allowance	1	2
E. Other (specify)	1	2

10 Are you involved in any of the following

	Yes	No
A. Self Help Groups	1	2
B. Microfinance Grou	1	2
C. Cash for Work schemes	1	2
D. Other (specify)	1	2

F. HEALTH AND ANTENATAL CARE

These questions are about your health

F.1. CASES ONLY (all ages)

Note to Interviewer: If participant screened positive via self report say:

Your responses to our earlier questions and examinations indicate that you may have difficulties in certain areas related to your health.

1 **What do you think is the cause of the difficulties you face in your health? (tick all that apply)**

1 = From Birth
2 = Trauma
3 = Illness
4 = Aging
5 = Other

2 How old were you when it started ☐☐ years

00 = from birth
99 = Don't know/refused

F2. All CASES AND CONTROLS

1 Have you had any serious health problems during the last twelve months? 0 = No 1 = Yes If NO, GO TO NEXT SECTION

2 If yes, what type of serious health event(or problem(s) did you experience during this period? (tick all that apply)

1= Severe Diarrhea (with dehydration or for more than 14 days)
2= Acute respiratory tract infection/pneumonia
3= Malaria
4= Eye Infection/eye problems
5= Ear infection/ear or hearing problems
6= Malnutrition
7= Vaccine-preventable disease (*including measles, chickenpox,*
8= *mumps, rubella, tetanus, TB, whopping cough)*
9= Chronic Illness
10= Accident/Injuries
11= Don't know/ no information provided
12= Other, specify .....

3 Where did you seek advice or treatment? 1 = did not seek advice or treatment If Response = 1, GO to Q4
2 = village/community health worker or agent
3= hospital
4= pharmacy
5= mobile clinic
6= private doctor
7= health centre/post
8= traditional healer
9= other, specify .....

ALL OTHER RESPONSES GO TO NEXT SECTION

4. If you did not seek advice or treatment, what was the reason? (3 answers possible)

Financial difficulties
1 = I was refused because I had no money (or not enough)
2 = I had difficulty to get food for myself during my stay
3 = I didn't have money for to pay for treatment
4 = I didn't have money for medication/objects
Transport, access difficulties
6 = there was no available transportation/it's very far away
7 = I had difficulty to find the money for trasnportation
8= No transport - refused travel on public transport
9 = I had difficulty to find someone to go with me because nobody had time to take me
10 = I did not ask anybody because I felt that it was a waste of time
Difficulties at the health service
11= I did not have the documents required to access health services
12 = there was no available medication
13 = there was no service available for my need (condition)
14 = I was refused because I am disabled
15= attitude of medical staff was negative
16 = The equipment that they gave is not very useful
17 = there is no female professional
18 = no difficulty
19 =other, specify _____

F3. REPRODUCTIVE HEALTH: Women aged 15-49 years only (all other respondents go to NEXT SECTION)

1 Do you have any children? 0 = No 1 = Yes If NO, go to Q3

2 How many children do you have today (excluding those who have died)? ☐☐

3 Did you have any pregnancies that ended before term (i.e. Still birth, miscarriage or abortion)? 0 = No 1 = Yes If NO, GO TO NEXT SECTION

4 If yes, how many pregnancies ended before term ☐

F4. PREGNANCY CARE:Women with Children under 5 only (all other respondents go to NEXT SECTION)

I would now like to ask you some questions about your children born in the last 5 years.

Note to Interviewer: If no children born in the last five years, go to next section

Please answer questions about the last child born in this period

5 Did you see anyone for antenatal care during this time? 0 = No 1 = Yes If NO, Go to Q7

6 Whom did you see? Anyone else?
Probe to identify each kind of person and record all mentioned

1 = Health personnel/Doctor
2 = Nurse/midwife
3 = Auxillary Midwife
4 = Traditional Birth Attendant
5 = Community/village health worker
6 = Other (please specify_____)

7 Where did you give birth to [name]?
Probe to identify source. If unable to determine if public/private sector write the name of the place
_____

1 = Home (Your home)
2 = Other home
3= Public sector Govt. hospital
4 = Public sector Govt. health centre
5 = Public sector Govt health post
6 = Other public sector (specify_____)
7 = Private medical sector/private hospital clinic
8 = Dispensary
9 = Other private medical sector (specify_____)
10 = Other (specify_____)

8 Who assisted with the delivery of [Name]?
Anyone else?
Probe for the types of person and record all mentioned.
If respondent says no one assisted, probe to determine whether any adults were present at delivery

1 = Doctor
2 = Nurse/Midwife
3 = Auxillary Midwife
4 = Traditional birth attendent
5 = Relative/friend
6 = Other (specify_____)
7 = No one assisted

9 Did [name] ever have any vaccinations to prevent him/her getting diseases, including vaccinations recieved in a national immunization coverage days 0 = No 1 = Yes

G REHABILITATION: Cases only

	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	1.1 Have you ever heard of this type of service?	1.2 Have you ever needed this service?	1.3 Have you ever recieved this service?	1.4 If yes, are you currently recieving or using it?	1.5 If reported needing (Yes to Q1.2) but not receiving a service (No to Q1.3), ask why have you not recieved it?	1.6 If reported once receiving/using service (Yes to Q1.3) but not receiving it now (No to Q1.4), ask why are you no longer recieving it?
		0 = No (go to next service) 1 = Yes	0 = No (go to next service) 1 = Yes	0 = No → Q1.5 1 = Yes → Q1.4	0 = No → Q1.6 1 = Yes (go to next service)	1 = Too expensive 2 = Too far/no transport 3 = Discriminating 4 = Communication bariers 5 = Don't know where to access 6 = Service not available 7= Other (specify)_____ **up to three responses allowe**	1 = Too expensive 2 = Too far/no transport 3 = Not 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 **up to three responses allowed**
a	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	0 1	0 1	0 1	0 1		
b	**Assistive devices service** (e.g. Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	0 1	0 1	0 1	0 1		
c	**Specialist educational services (e.g. therapist, school support services)**	0 1	0 1	0 1	0 1		
d	**Vocational Training** (e.g. Employment skills training, etc.)	0 1	0 1	0 1	0 1		
e	**Counselling for person with a disabiliy** (e.g. Physchologist, psychiatrist, counsellor)	0 1	0 1	0 1	0 1		
f	**Counselling for parent/family**	0 1	0 1	0 1	0 1		
g	**Welfare services** (e.g. social worker, disability grant, etc)	0 1	0 1	0 1	0 1		
h	**Health services** (e.g. at a primary health care clinic, hospital, home health care services etc.)	0 1	0 1	0 1	0 1		
i	**Health information** (e.g. From the radio, tv, at schools, clinics, hospital etc.)	0 1	0 1	0 1	0 1		
j	**Traditional healer/faith healer**	0 1	0 1	0 1	0 1		
k	**Legal advice**	0 1	0 1	0 1	0 1		
l	**Specialist health services** (e.g. Surgery, ear/eye medical, psychiatry services)	0 1	0 1	0 1	0 1		

H. ASSISTIVE DEVICES: Cases only

Note to Interviewer: Read list of devices that are relevant to difficulty categories of impairment

		1.1 I am going to read you a list of assistive devices. For each please tell me if you use it, need it but don't use it, or don't need it	1.2 If used, is it in good working order?	1.3 If used, where did you get the assitive device?	1.4 If reported, needing but not using:what is the main reason why don't you use it?
Difficulty category	**Device**	1 = Use it 2 = Need it, but don't use it -> Q 1.4 3 = Don't need/NA -> next device 4 = Don't know what it is -> Next device	1 = Yes 0 = No 3 = N/A	1 = Private provider 2 = Government health service 3 = Government service (not health) 4 = NGO 5 = Friend/relative 6 = Other 7 = Don't know Next device	1 = Not really helping me 2 = Not satisfied with device 3= No longer need the device 4=Broken and unable to repair (cost) 5=Broken and unable to repair (too far) 6= Broken and unable to repair (not available)
Seeing	a. Eye Glasses				
	b. Magnifying glass				
	c. Telescoping Lenses/glasses				
	d. Enlarge print				
	e. Braile				
	f. Other, specify				
Hearing	g. Hearing Aid				
	h. Computer				
Mobility	i. Wheel chair				
	j. Crutches				
	k. Walking stick				
	l. White cane				
	m. Guide				
	n. Standing Frame				
	o. Other, specify				

2. Do you use any other assitive devicees 0 = No — Go to Q4
1 = Yes — Go to Q3

3. If yes, please tell me what they are: CODE: if other specify _____
(use device list below)

4. Are there any assistive devices you think you need but do not have? 0 = No — End
1 = Yes — Go to Q 5

5. If yes, please tell me what they are: CODE: if other specify _____
(use device list below)

Eyeglasses = 1	Walking Stick = 4	Walking Frame = 7	Amplified Telephone = 10	Computers and/or special computer softwa
Hearing Aid = 2	White cane = 5	Communicati on Board = 8	Toilet Seat Raiser = 11	Others (specify)
Wheelchair = 3	Crutches = 6	Braille = 9	Bath and shower seats = 12	

I ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS
(all cases and controls)

1 ACTIVITY LIMITATION
I would like to know how difficult it is for you to perform this activity WITHOUT any kind of assistance at all? (Without the use of assistive devices - either technical or personal)

		No difficulty	Moderate difficulty	Severe difficulty	Unable to do	Dont Know
a	watching/looking/seeing	1	2	3	4	5
b	listening/hearing	1	2	3	4	5
c	learning to read/write/count/calculate	1	2	3	4	5
d	acquiring skills (manipulating tools, painting, carving etc.)	1	2	3	4	5
e	thinking/concentrating	1	2	3	4	5
f	reading/writing/counting/calculating	1	2	3	4	5
g	solving problems	1	2	3	4	5
h	understanding others (spoken, written or sign language)	1	2	3	4	5
i	producing messages (spoken, written or sign language)	1	2	3	4	5
j	communicating directly with others	1	2	3	4	5
k	staying in one body position	1	2	3	4	5
l	changing a body position (sitting/standing/bending/lying)	1	2	3	4	5
m	transferring oneself (moving from one surface to another)	1	2	3	4	5
n	lifting/carrying/moving/handling objects	1	2	3	4	5
o	fine hand use (picking up/grasping/manipulating/releasing)	1	2	3	4	5
p	hand & arm use (pulling/pushing/reaching/throwing/catching)	1	2	3	4	5
q	walking	1	2	3	4	5
r	moving around (crawling/climbing/running/jumping)	1	2	3	4	5

PARTICIPATION RESTRICTION
2 Do you have any difficulty performing this activity in your current environment? Now I would like to know whether you have difficulties even with the help of assistive devices or another person
[Current environment where you live, work and play etc for the majority of your time]

		No difficulty	Moderate difficulty	Severe difficulty	Unable to do	Dont Know
a	washing oneself	1	2	3	4	5
b	care of body parts, teeth, nails and hair	1	2	3	4	5
c	toileting	1	2	3	4	5
d	dressing and undressing	1	2	3	4	5
e	eating and drinking	1	2	3	4	5
f	shopping (getting goods and services) **ABOVE 8 ONLY**	1	2	3	4	5
g	preparing meals (cooking) **ABOVE 8 ONLY**	1	2	3	4	5
h	doing housework (washing/cleaning) **ABOVE 8 ONLY**	1	2	3	4	5
i	taking care of personal objects (mending/ **ABOVE 8 ONLY**	1	2	3	4	5
j	taking care of others	1	2	3	4	5
k	making friends and maintaining friendships	1	2	3	4	5
l	interacting with persons in authority (offi **OVER 16s ONLY**	1	2	3	4	5
m	interacting with strangers	1	2	3	4	5
n	creating and maintaining family relationships	1	2	3	4	5
o	making and maintaining intimate relation **OVER 16s ONLY**	1	2	3	4	5
p	going to school and studying (education) **UNDER 16s ONLY**	1	2	3	4	5
q	getting and keeping a job (work & employment) **OVER 16s ONLY**	1	2	3	4	5
r	handling income and payments (economi **OVER 16s ONLY**	1	2	3	4	5
s	clubs/organisations (community life) **OVER 16s ONLY**	1	2	3	4	5
t	recreation/leisure (sports/play/crafts/hobbies/arts/culture)	1	2	3	4	5
u	religious/spiritual activities **OVER 16s ONLY**	1	2	3	4	5
v	political life and citizenship **OVER 16s ONLY**	1	2	3	4	5

J. **Environment questions (<u>All cases and controls</u>)**

Being an active, productive member of society includes participating in such things as working, going to school,taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or or improve a person's participation in these activities while other factors can act as barriers and limit participation.

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem daily, weekly, monthly, less than monthly, or never. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

In the past 12 months how often:	Daily	Weekly	Monthly	Less than monthly	Never	N/A	**When problem occurs, has it been a**	
							Big problem	Little Problem
a. has the availability/accessibility of transportation been a problem for you?	1	2	3	4	5	6	1	2
b. has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2
c. have other things in your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2
d. has the information you wanted or needed not been available in a format you can use or understand	1	2	3	4	5	6	1	2
e. has the availability of health care services and medical care been a problem for you?	1	2	3	4	5	6	1	2
f. Did you need someone else's help in your home and could not get it easily?	1	2	3	4	5	6	1	2
g. did you need someone else's help at school or work and could not get it easily?	1	2	3	4	5	6	1	2
h. Have other people's attitudes toward you been a problem at home?	1	2	3	4	5	6	1	2
i. have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	6	1	2
j. did you experience prejudice or discrimination	1	2	3	4	5	6	1	2
k. did the policies and rules of businesses and organizations make problems for you?	1	2	3	4	5	6	1	2
l. did government programs and policies make it difficult to do what you want or need to do?	1	2	3	4	5	6	1	2

Appendix 4: Stakeholder Role Mapping – India

Stakeholder	Contact	Role
Regional Government	SERP Regional Director	Facilitate meetings with district level stakeholders
District level Government (Mahbubnagar)	District Collector	1. Facilitate meetings with other stakeholders through written permission/approval for project 2. Assist in providing contacts for local newspapers to share project protocol with communities in advance 3. Sign letter of approval for village leaders to accommodate project in relevant villages 4. Provide written permission/approval for project and written request to government health services to facilitate referrals
	SERP District Coordinator	Provide written authorisation for SERP Mandal offices to assist project in identification of additional cases and referral of PWD identified by project
	Mahbubnagar DMHO	1. Provide written permission/approval for project and written request to Govt. Health services to facilitate referrals 2. Provide list of Government health services in district 3. Give permission for signature to be put on referral card
	Aarogyshra Registry Coordinator	1.Provide written permission/approval for project 2. Provide written request to Aarogy Mithra to assist project field team 3. Provide contact details for Aarogy Mithra in relevant mandals
	District Disability Officer	1. Provide written permission/approval for project 2. Provide list of any other disability relevant services beyond Government Hospitals

	ASHA Coordinator	1. Provide written request to ASHA workers to assist project field team 2. Provide contact details for ASHA workers in relevant villages 3. Assist in circulating information about project in advance to relevant villages
District level Service Providers	District Government Hospitals	Provide details of services available and costing structures
	District NGO services	Provide details of services available and costing structures
	District Private services w/ Aarogyshra Registry Insurance Card	Provide details of services available and costing structures
Mandal level Government	SERP Mandal Offices	Assist in identification of additional cases and agree to referrals of PWD identified by project to SERP SHGs
	Aarogy Mithra	Agree to follow up on referrals of PWD identified by project
Village level	All village leaders	Provide vocal permission to conduct survey in village and facilitate identification of community centre to hold survey
	ASHA workers	1. Spread information to village heads and communities about project in advance 2. Assist enumerators in identifying and mobilising participants and additional cases

Appendix 5: Washington Group Recommendations for Indicators 2016

Draft indicators for anxiety, depression, pain, fatigue and upper body were shared by members of the Washington Group at the annual Washington Group Meeting 2016. Draft indicators combine questions related to frequency and intensity of feelings attributed to each domain. The table below provides an example of the indicator design.

		Frequency of Feelings				
		Daily	Weekly	Monthly	A Few Times a Year	Never
Intensity of Feelings	Not Asked					4
	A Little	3	3	3	4	4
	In Between	2	3	3	4	4
	A lot	1	2	3	4	4

Appendix 6: Final UNICEF Module

The final UNICEF/ Washington Group Module on Child Functioning was released in October 2016 and is available from: https://data.unicef.org/resources/module-child-functioning/

THE FINAL MODULES FOR CHILDREN 2 – 4 AND 5 – 17 ARE ATTACHED BELOW.CHILD FUNCTIONING (AGE 2-4) CF		
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (*name*) WEAR GLASSES?	Yes .....1 No 2	 2⇨CF3
CF2. WHEN WEARING HIS/HER GLASSES, 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
CF3. 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	
CF4. DOES (*name*) USE A HEARING AID?	Yes .....1 No 2	 2⇨CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? 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
CF6. DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? 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	
CF7. DOES (*name*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes .....1 No 2	 2⇨CF10

CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty .....2 A lot of difficulty .....3 Cannot do at all 4	
CF9. WITH HIS/HER EQUIPMENT OR ASSISTANCE, 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	1⇨CF11 2⇨CF11 3⇨CF11 4⇨CF11
CF10. COMPARED WITH 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	
CF11. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND? 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	
CF12. DOES (*name*) HAVE DIFFICULTY UNDERSTANDING YOU? 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	
CF13. WHEN (*name*) SPEAKS, DO YOU HAVE DIFFICULTY UNDERSTANDING HIM/HER? 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	

CF14. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY LEARNING THINGS? 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	
CF15. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY PLAYING? 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	
CF16. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES (*name*) KICK, BITE OR HIT OTHER CHILDREN OR ADULTS? WOULD YOU SAY: NOT AT ALL, THE SAME OR LESS, MORE OR A LOT MORE?	Not at all .....1 The same or less .....2 More .....3 A lot more 4	

CHILD FUNCTIONING (AGE 5-17)		CF
CF1. 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
CF2. 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
CF3. 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	
CF4. DOES (*name*) USE A HEARING AID?	Yes .....1 No 2	 2⇨CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? 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
CF6. DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? 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	
CF7. DOES (*name*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes .....1 No 2	 2⇨CF12
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL		

GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty .....2 A lot of difficulty .....3 Cannot do at all 4	 3⇨CF10 4⇨CF10
CF9. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty .....2 A lot of difficulty .....3 Cannot do at all 4	
CF10. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. 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	 3⇨CF14 4⇨CF14
CF11. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. 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⇨CF14
CF12. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL		

FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. 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	 3⇨CF14 4⇨CF14
CF13. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. 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	
CF14. 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	
CF15. WHEN (*name*) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD? 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	
CF16. WHEN (*name*) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF THIS HOUSEHOLD? 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	

CF17. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY LEARNING THINGS? 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	
CF18. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY REMEMBERING THINGS? 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	
CF19. DOES (*name*) HAVE DIFFICULTY CONCENTRATING ON AN ACTIVITY THAT HE/SHE ENJOYS DOING? 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	
CF20. DOES (*name*) HAVE DIFFICULTY ACCEPTING CHANGES IN HIS/HER ROUTINE? 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	
CF21. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY CONTROLLING HIS/HER BEHAVIOUR? 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	
CF22. DOES (*name*) HAVE DIFFICULTY MAKING FRIENDS?	No difficulty .....1 Some difficulty .....2 A lot of difficulty 3	

WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Cannot do at all 4	
CF23. HOW OFTEN DOES (*name*) SEEM VERY ANXIOUS, NERVOUS OR WORRIED? 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	
CF24. HOW OFTEN DOES (*name*) SEEM VERY SAD OR DEPRESSED? 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	

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