International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

GUATEMALA NATIONAL DISABILITY STUDY

(ENDIS 2016)

SURVEY REPORT

Funders: CBM
Conadi Guatemala
UNICEF Guatemala

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This report, as well as the Study Summary Report, Qualitative Report and Reports in Spanish, can be downloaded at http://disabilitycentre.lshtm.ac.uk

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Acronyms

CONADI	Consejo Nacional para la Atencion de las Personas con Discapacidad
aOR	Adjusted Odds Ratios
ENDIS	National Survey of Disability in Guatemala
ICED	International Centre for Evidence in Disability
ICF	International Classification of Functioning, Disability and Health
INE	Guatemala Instituto Nacional de Estadistica (National Statistical Office of Guatemala)
LSHTM	London School of Hygiene & Tropical Medicine
OR	Odds ratio
PEEK	Portable Eye Examination Test
PHQ-9	Patient Health Questionnaire
PPT	Physical Performance Test
QoL	Quality of life
SD	Standard Deviation
SES	Socio-economic status
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WASH	Water Sanitation and Hygiene
WG	Washington Group on Disability Statistics
WHO	World Health Organisation
WHO	World Health Organisation
95% CI	95% Confidence Intervals
CONADI	Consejo Nacional para la Atencion de las Personas con Discapacidad

1. Executive Summary

Background

Disability disaggregated population data and understanding the lived situation for people with disabilities is important for informing and motivating evidence based advocacy, policy and service planning. The Guatemala National Disability Survey (ENDIS) was undertaken to address a need for up to date reliable data on disability in Guatemala.

Study objectives

- To estimate national and regional disability prevalence among adults and children in Guatemala
- To explore the lived experience of disability in terms of socio-economic status, quality of life, participation, health and opportunities to go to school and work amongst people with and without disabilities
- To explore cultural, ideological, and social interpretations and responses to disability; provide insight into the disability and poverty relationship; and examine social, political, and economic dimensions operating within this relationship.

Methods overview

The study had three components:

1. A **population based survey** to estimate the prevalence of disability
2. A **case-control study** to compare people with and without disability
3. A **qualitative study** to explore the conceptual, cultural and social intersections of disability and the disability and poverty relationship

Population based survey

Using standard sampling methodology, 280 clusters of 50 people (aged >2 years) were selected throughout the country (total 13,800). All participants were assessed for disability as follows:

- Self-reported functioning: Participants were interviewed using the Washington Group Extended Set of questions for adults and UNICEF/Washington Group extended set of questions for children. These included functional domains related to seeing, hearing, walking, upper body strength, communication, cognition, self-care, depression and anxiety
- Clinical impairment: Any participant reporting 'some' or greater difficulty in seeing, hearing, mobility or with anxiety or depression, were screened for a clinical impairment in the same domain. For example, if they reported 'some' or worse difficulties with seeing, their visual acuity was assessed.

For the purposes of the survey, people were categorised as having a disability if they:

- Reported "a lot of difficulty" or "cannot do" in one of the core domains of the Washington Group/UNICEF questionnaires and/or
- Reported at least "some difficulty" with vision, hearing, mobility, anxiety and depression AND had a moderate or worse clinical impairment in that domain.

Case-control study

All participants aged ≥5 years identified in the survey as having a disability based on the Washington Group questions ('cases') were invited to participate in this nested case-control study. For each person with a disability, one person the same age, sex and cluster without a disability ('controls') was also selected. Participants were interviewed about socio-demographics, livelihoods, education, health, water and sanitation, quality of life and participation. People with disabilities were also asked about access to and awareness of rehabilitation services, assistive devices and rights.

Qualitative component

In-depth interviews were conducted with 27 disabled people and family members in four rural areas (indigenous and non-indigenous). A thematic analysis was used in the bid to find common themes and patterns in the data. A detailed report for this component can be found at http://disabilitycentre.lshtm.ac.uk

Key findings from the national survey

Prevalence of disability

- A total of 13,073 people participated in the survey (response rate: 88%)
- The overall prevalence of disability, defined as reporting "a lot of difficulty" or "cannot do" in any Washington Group domain, or reporting "some difficulty" in any domain plus screening positive for a moderate or above clinical impairment, was 10.2% (95% CI 9.3 – 11.2)
- Disability prevalence increased by age and was 24.1% (21.9 – 26.5) among adults aged over 50 years
- The prevalence of disability was higher for women compared to men amongst adults, but not amongst children.
- There were regional differences in estimated prevalence with the highest prevalence in Central and North West and lowest in North East and South East.
- Comparing people with and without disabilities from the survey, people with disabilities were more likely to be in the poorest socio-economic group, had lower access to education and were less likely to have ever married/lived with a partner.

Prevalence by functional domain

- Looking separately by functional domain, prevalence of significant limitations among adults was highest in the domains of anxiety/depression (9.3%) mobility (8.0%), seeing (4.2%) and hearing (4.0%). Amongst children, the domains with highest reported significant limitations were anxiety (1.9%), mobility (1.0%) and maintaining relationships (1.0%).

Households with members with a disability

- Nearly a third (31%) of the 3095 households in the survey included at least one household member with a disability.

- These households were significantly more likely to be in the lowest socio-economic status group, had larger household size, higher dependency ratio and a lower proportion of household members who were working compared to households without a member with a disability

Key findings from the case control study

Socio-demographics

- Adults with disabilities were significantly less likely to have attended school (64%) and were more likely to be illiterate (37%) compared to adults without disabilities (72% and 25% respectively).
- Children with disabilities were half as likely to have their biological father living in the same home as them compared to children without disabilities.

Children and education

- Overall, 83% of children without and 76% of children with disabilities were attending school.
- In rural areas, children with disabilities were significantly less likely to be attending school (61%) compared to children without disabilities (82%). In urban areas, school attendance was over 80% for both children with and without disabilities
- School attendance was significantly lower among girls with disabilities (69%) compared to girls without disabilities (84%). These differences were not significant among boys.
- Among children with disabilities only:
    - School attendance among children was much higher in urban compared to rural areas
    - School attendance was lowest for children with significant limitations in physical and cognitive functioning

Work and Employment

- Adults with disabilities were significantly less likely to have worked in the previous week (23%) compared to adults without disabilities (47%).
- Adults with disabilities had less stable livelihood opportunities: they were significantly more likely to report working only occasionally (30%) compared to people without disabilities (19%).
- There were significant differences in reported reasons for not working: others (household members/ employers) not allowing and poor health were more commonly reported by people with disabilities
- Adults with disabilities were more likely than adults without disabilities to report having a retirement pension (20% vs 10%) and family allowance (14% vs 8%).
- Access to non-state support (social security benefits, cash for work schemes and remittances) was low for people with and without disabilities (<5%).
- Among adults with disabilities, the likelihood of work was significantly lower among:
    - Older adults (>50 years)
    - Females compared to males
    - People who had never married/lived with a partner
    - People with significant physical functional limitations

Water Sanitation and Hygiene

- Access to improved[1] sanitation and water supplies was high for both households with (89%) and without a person with a disability (84%)
- Persons with disabilities were slightly less likely to use toilet facility (75%) without assistance compared to people without (84%) and without faecal contact (71% vs 76%).

Participation and environment

- Overall, people with disabilities had significantly higher participation restrictions compared to people without disabilities in the areas of independent or supported self-care, domestic life, interpersonal behaviours, major life areas (school and work) and community/civic life areas.
- Among people with disabilities:
    - Significantly greater participation restrictions were found among older adults, males, people living in the North East and South East regions, adults who were widowed/divorced or never married/lived with a partner and adults with no formal education.
    - Participation scores were lowest for people with significant limitations in physical, communication and multiple domains, older adults and those who were widowed/divorced
- In general, people with disabilities reported greater environmental barriers across different environmental domains (such as transport, the natural environment and availability and accessibility of services) and across each age group.

Quality of life

- Quality of life scores were significantly poorer for people with disabilities
- Among people with disabilities:
    - Being poorer, living in rural areas and living in the North East and South East regions was associated with having significantly worse quality of life.
    - People reporting significant limitations with physical, cognitive, anxiety/depression, communication, and multiple domains reported worse quality of life compared to people without significant limitations in the corresponding domains/group

Health

- People with disabilities were more likely to have reported a serious health problem in the past 12 months
- There were no significant differences in health seeking behaviour between people with and without disabilities (whether sought care and place of care)
- In terms of experience of health-care, people with disabilities were more likely to report being disrespected and more likely to find it difficult to understand information given to them at health centres.
- Women of reproductive age (15-49 years) with disabilities were less likely to have sought antenatal care in their last pregnancy (with the past 5 years). However, they were more likely than

1 'Improved' defined according to the WHO/UNICEF Joint Monitoring Programmeas water source being protected from outside contamination, and the sanitation facility separating human exreta from human contact. (see wssinfo.org)

women without disabilities to have delivered their baby in a health centre or hospital (rather than at home) and to have the birth assisted by a doctor.

- No major differences were observed between numbers of children or vaccination status of their children between women with and without disabilities.
- Vaccination coverage was high for both children with and without disabilities

Disability and rehabilitation (among people with disabilities only)

- Illness (30%), aging (18%) and trauma (15%) were the most commonly reported causes of disability
- Awareness and perceived need of rehabilitation services amongst people with disabilities was relatively low (table 5)
- Overall reported use of assistive devices was low. Perceived unmet need was highest for vision aids (glasses and magnifying glass) and hearing aids.

Key findings from Qualitative Report

- Disability is heterogeneous and complex
- Social attitudes and responses to disability exist on a spectrum that is not systematically stigmatised
- Many people with disabilities and their families live in situations of extreme poverty, with constrained livelihood opportunities, infrastructure barriers and profound isolation
- Lack of access to safety nets is a key concern, which must be addressed

1.1 "..look around you, there is no work, the houses have water and animals coming in, and we have no money and sometimes no food, our children go hungry, hospitals treat us like dirt… and then comes this cursed illness, you have to pay money for doctors and you can't and then you can't buy food, what can I tell you? Look around you, how do you expect someone like me to survive here?" (Manuel)

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2. Introduction

Worldwide there are estimated to be over one billion people living with some form of disability, which is approximately 15% of the world's population[1]. The majority of people with disabilities (80%) are thought to be living in low and middle income countries. People with disabilities can be defined as those who have long-term physical, mental and intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, may hinder their full and effective participation in society on an equal basis with others[2].

Evidence shows that people with disabilities are more likely to face exclusion from education and employment, compared to their peers without disabilities, leading to an increased risk of poverty. They are also more likely to face restrictions in participation in society compared to people without disabilities, including reduced access to education and health care[1].

A National Survey of Disability (ENDIS) was completed in Guatemala in 2005, funded by the Inter-American Development Bank (IDB)[3]. The survey estimated a national prevalence of disability of 4.2%, however the methods used to define disability in the study did not reflect international standards and recommendations. Moreover, changing population demographics in Guatemala, including population ageing, warrant updated, disaggregated, population prevalence estimates.

Particularly in light of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the 2030 Sustainable Development Agenda focus on "leaving no one behind", there is a need for up to date data on disability in Guatemala[4 5]. Disability disaggregated population data and understanding the lived situation for people with disabilities is important for informing and motivating evidence-based advocacy, policy and service planning. These data are needed to support the full inclusion of people with disabilities in Guatemala, as well as to support disability specific services and as a baseline against which to assess change.

There is also a need to address the lack of critical qualitative research on disability in Guatemala, especially one that engages with and recognises the deep contextual, cultural, personal and other complexities and heterogeneities of the disability experience[6]. Poverty and disability are frequently postulated to be inter-linked, but in-depth explorations of this relationship and the dynamics operating within are lacking, particularly in rural, poor communities (ibid, 2015). While disability statistics are essential to aggregate, provide robust and representative estimates, it is also imperative to understand the lived experience of disability in a more contextualised way, by speaking directly to people with disabilities and their families and learning about and from their experiences in their own words.

CONADI, alongside CBM Latin America, UNICEF Guatemala and the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine have therefore undertaken a National Survey of Disability (ENDIS 2016) to meet this data need.

2.1 Disability in Guatemala

In 1996, Decree 135-96 of the Republic of Guatemala Congress was approved, including the Law on Attention to Persons with Disabilities. Among other things, these regulations are intended to serve as a legal instrument to support maximum development, social participation and the exercise of rights and duties for people with disabilities in Guatemala; guarantee equal opportunities for people with disabilities in areas such as health, education, work, recreation, culture, sports and others; and, eliminate any type of discrimination.

In 2006, a National Policy on Disability was approved, the main objective of which was to create opportunities for integration and participation in Guatemalan society for people with disabilities. However, despite these laws and polices, people with disabilities in Guatemala continue to experience physical barriers, discrimination and social exclusion. The law is not fulfilled, and a lack of resources to implement policy means that the reality for people with disabilities is not transformed.

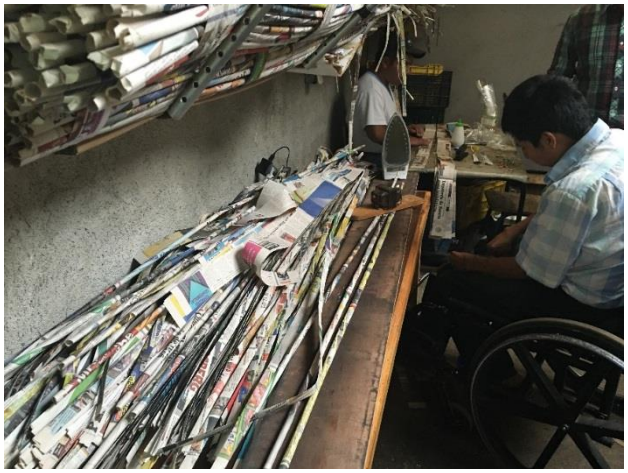


Photo 1: A young man works in a workshop

2.2 Measuring Disability

Key Messages in this section:

- **Disability is understood in the International Classification of Functioning, Disability and Health as the interaction between health conditions and/or impairments in body function and structure, activity limitations and participation restrictions**
- **Several approaches to disability measurement for population based surveys exist, focusing on different components of disability including self-reported disability, self-reported functioning and clinical assessment of impairments**
- **Previous research by ICED has recommended a combined approach, measuring self-reported functional limitations together with clinical screens for impairments in vision, hearing, musculoskeletal system and depression**

What is disability?

The conceptualisation of disability is complex and has changed over time. Most historically, the medical model of disability, viewed disability purely as a medical phenomenon determined by an individual having an impairment in body functioning or structure (e.g. the presence of mobility or visual impairments). The social model views disability as the external cultural, physical, social and economic restrictions placed by society on people with impairments. The human rights model, as advocated by the UN Convention of the Rights of Persons with Disabilities calls for socio-political participation by people with disabilities, and for control over their own lives. It goes beyond a focus on removing barriers, called for by the social model, and argues that full participation is a human right.

The most widespread conceptualisation, currently, is the International Classification of Functioning, Disability and Health (ICF) which was developed by the World Health Organisation (WHO). This is the framework adopted by ENDIS. This framework aims to bridge the factors both internal and external to the individual through incorporating health conditions, functional impairments, activity limitations and participation as well as the environment (Figure 1). Specifically, the ICF defines disability as the interaction between:

- Health conditions and/or impairments in body function and structure
- Activity limitations
- Participation restrictions

The relationship between these components is strongly mediated by contextual factors related to both the environment and the individual.

For example, spina bifida (a congenital health condition) may cause leg muscle weakness (body function and structure) limiting a child's ability to walk (activities). The child may be unable to attend school (participation restrictions) because of environmental factors (e.g. the local school is not accessible) or personal factors (e.g. self-esteem).

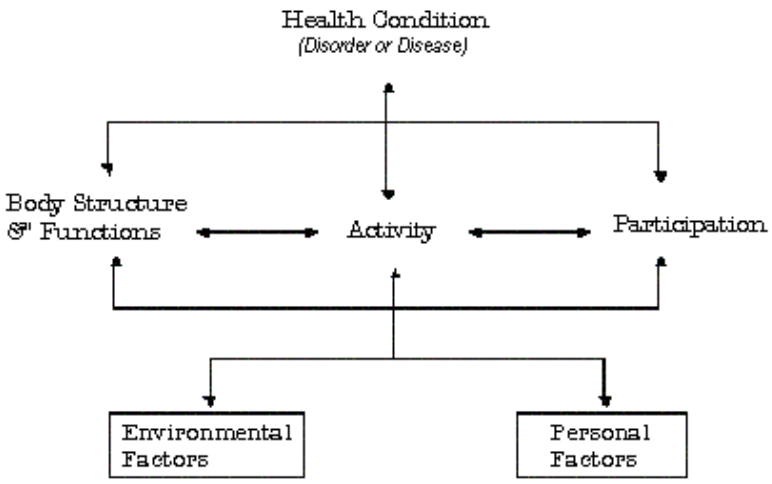


Figure 1: The International Classification of Functioning, Disability and Health (ICF)

The ICF is used to define disability in the 2006 United Nations Convention on the Rights of Persons with Disabilities as:

"long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder [a person's] full and effective participation in society on an equal basis with others".

Measuring disability in surveys

Reflecting these complexities of defining disability, many different methods have been used to measure it in previous surveys. This has made it difficult to compare disability data over time or between settings. There is now a strong movement to collect comparable data, which is advocated for by the World Report on Disability, as well as the 2030 sustainable development discussions.

There are three common approaches to measuring disability in surveys. These include a single direct question e.g. "do you consider yourself to have a disability". This is simple and quick, however is likely to result in significant under-reporting due to stigma and cultural perceptions of disability, and is not considered adequate for generating comparable prevalence estimates for survey purposes.

Another approach is the assessment of impairments or health conditions e.g. visual acuity. Objective screening criteria produces reliable and comparable data on cause and severity, which can aid service planning and policy formulation. However, impairment data alone may not capture how the individual functions in his or her environment and the overall experience of disability. Historically, impairment surveys have also been comparatively expensive because of a reliance on clinicians and specialist equipment. Recent advances in technology however are increasing the ability of non-clinical interviewers to undertake short screens of hearing, vision and mobility alongside self-reported functioning tools.

A third approach is self-reported functioning. This approach asks people whether they experience difficulties in different areas of functioning e.g. difficulties in seeing or hearing, focussing on the "activities" component of the ICF. Participants respond on a scale from "no difficulty", to "some difficulty", "a lot of difficulty" or "cannot do at all". The method recognises the range of functional limitations that people with the same impairment may have. It also maximises the information that can be collected at low cost. This is the approach used by the Washington Group (WG) on Disability Statistics, who have developed several survey modules on functioning. These include a short set of questions developed for censuses which measures difficulties in the domains of seeing, hearing, walking, cognition, communicating and self-care. More recently the WG have developed an extended set for use in surveys which include additional questions on the core domains as well as additional domains: affect (anxiety and depression) and upper -body function, pain and fatigue. The WG together with UNICEF have also developed an extended set of questions functioning for children aged 2 to 17 years. Use of the WG tools to collect comparable statistics on disability has been formally endorsed by the Inter-Agency Expert Group on Sustainable Development Goal Indicators, the UK Department for International Development, the Australian Department for Foreign Affairs and Trade, and others. The International Centre for Evidence in Disability (ICED) has used these tools in a number of previous surveys of disability in Haiti, India and Cameroon[7 8].

Measuring disability in ENDIS

Previous research by ICED has shown that a combined approach, incorporating both self-reported functioning tools and clinical impairment screens, will capture a broader spectrum of individuals experiencing participation restrictions than either tool used in isolation[8]. We determined in two studies in Cameroon and India that tools to assess reported functional limitation alone would not identify all persons with underlying health conditions or impairments that impact on their participation. However, using 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 previous study's 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.

This approach was undertaken in ENDIS 2016. All participants reporting at least "a lot" of difficulty in any core domain were considered to have a disability in this study. All participants aged 5+ who reported "some" or greater difficulty in either vision, hearing, walking or (aged 18+) anxiety/depression also underwent a clinical screen for the corresponding domain (e.g. a person who reported some problems with seeing, had their visual acuity tested). Any participant identified to have a moderate or worse impairment based on the clinical screen was also included in the prevalence estimate. See Table 1 below.

ENDIS 2016 Disability Prevalence Estimate Methodology (based on Mactaggart et al. 2016)

Table 1: ENDIS 2016 Prevalence Estimate Methodology

		Response		
Age Group	**WG Domains**	**"none"**	**"some"**	**"a lot or can't do"**
2-4	Seeing, Hearing, Walking, Fine Motor, Understanding, Being Understood, Learning, Playing, Behaviour	Not included	Not included	Include in prevalence estimate
5-17	Seeing, Hearing and Walking	Not included	Conduct clinical screen and include in prevalence estimate only if moderate impairment or greater identified	Include in prevalence estimate and collect further information via corresponding clinical screen
	Self-Care, Understanding, Being Understood, Learning, Remembering, Anxiety, Depression, Controlling Behaviour, Concentrating, Accepting Change, Relationships	Not included	Not included	Include in prevalence estimate
18+	Seeing, Hearing, Walking, anxiety and depression	Not included	Conduct clinical screen and include in prevalence estimate only if moderate impairment or greater identified	Include in prevalence estimate and collect further information via corresponding clinical screen
	Communication, Cognition, Self Care, Upper body	Not included	Not included	Include in prevalence estimate
	Pain, Fatigue	Not included		

3. Study Aims

The objectives of ENDIS were:

- To estimate the national disability prevalence among adults and children in Guatemala, and to provide regional estimates for 5 broad regions
- To disaggregate the prevalence of disability in Guatemala by age, sex, type of functional limitation and socio-economic status
- To document the proportion of individuals with moderate or above visual, hearing and physical impairment in the country, or experiencing clinical depression
- To explore the lived experience of disability in terms of socio-economic status, quality of life, participation, health and opportunities to go to school and work amongst people with and without disabilities
- Tto explore cultural, ideological, and social interpretations and responses to disability; provide insight into the disability and poverty relationship; and examine social, political, and economic dimensions operating within this relationship.

Photo 2: Guatemala Field work

4. Methods

Study setting:

The study was conducted across all 22 departments of Guatemala. For the purposes of the study, Guatemala was divided into 5 regions comprising roughly equal proportions of the national population (see Figure 2 below): Central, North East, South East, South West and North West.

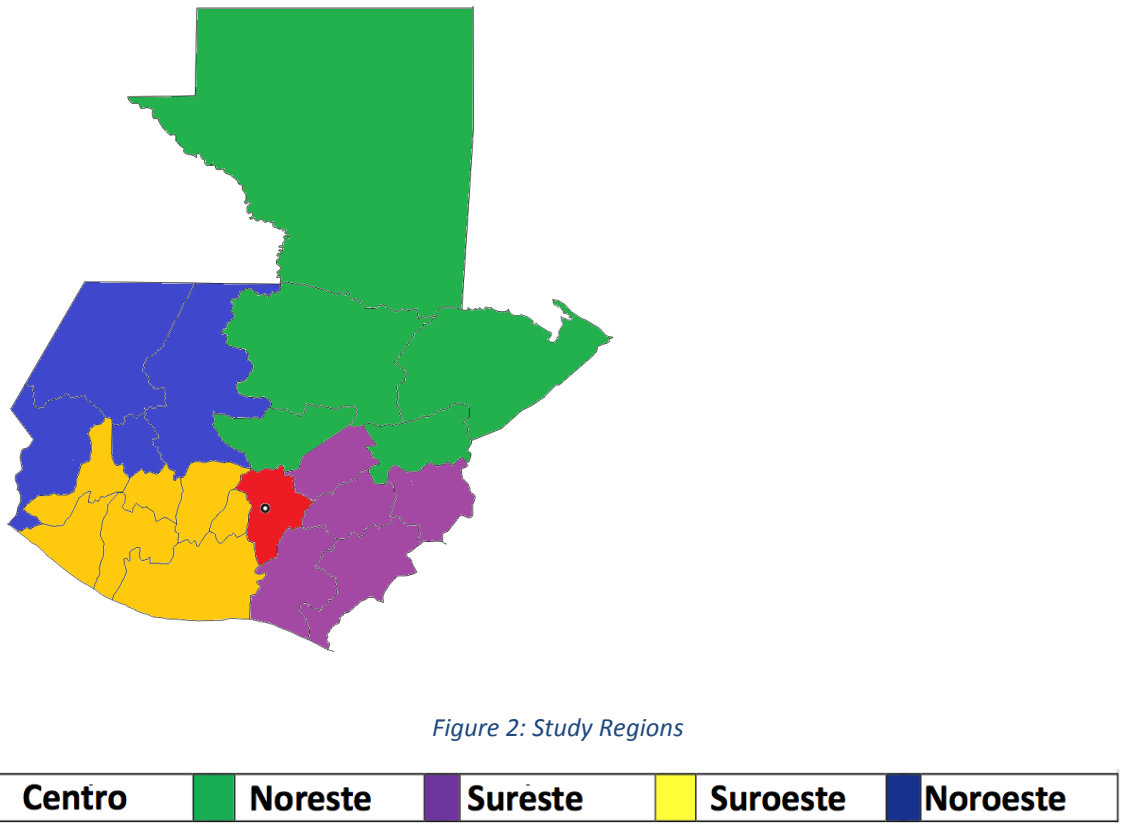


Figure 2: Study Regions

Study methods overview:

The study has three components:

1. A **population based survey** to estimate the prevalence of disability
2. A **case-control study** to compare people with and without disability in terms of their socio-economic status and their use of education, health, water and sanitation and employment services.
3. A **qualitative component** to explore the conceptual, cultural and social dimensions of disability by prioritising the voices and perceptions of persons with disabilities

Population based Survey

Using standard sampling methodology we selected 280 clusters of 50 people throughout the country. In each cluster all eligible survey participants (aged 2+) were interviewed for self-reported disability (ages 2-10 reported via proxy).

All participants reporting at least "a lot" of difficulty in any core domain were considered to have a disability. All participants aged 5+ who reported "some" or greater difficulty in either vision, hearing, walking or (aged 18+) anxiety/depression also underwent the corresponding clinical screen. Amongst these, all participants identified to have a moderate or worse impairment according to the clinical screen were also included in the disability prevalence estimate (see Section 1.2 on Measuring disability in ENDIS).

The clinical screens used were:

- Vision: Visual Acuity Testing using **PEEk Acuity**
- Hearing: Pure Tone Audiometry Testing using **HearTest**
- Walking/climbing: Physical functioning test using **Physical Performance Test (PPT)**
- (Age 18+) Anxiety/Depression: Clinical depression test using the **Patient Health Questionnaire (PHQ-9)**

Case control study

In Public Health Research, a Case Control study refers to a method that compares participants with an outcome of interest ("cases") with participants who do not have the outcome of interest ("controls"). In this study, the outcome of interest is disability, "cases" are people who were identified to have a disability during the National Survey, and "controls" are members of the same community without a disability matched to each person with a disability based on their sex and age-range.

All participants aged ≥5 years who screened positive for self-reported disability in the survey (**'cases'**) were invited to participate in a nested case-control study. For each case, one '**control'** of the same age, sex and cluster without a disability was also selected. Cases and controls were interviewed about socio-demographics, poverty, livelihoods, education, health, water and sanitation, activities and participation. People with disabilities were also asked about perceived cause and history of disability and access to and awareness of rehabilitation services, assistive devices and rights.

Qualitative Component

The qualitative component sought to explore cultural, ideological, and social interpretations and responses to disability; provide insight into the disability and poverty relationship while examining social, political, cultural, economic and other dimensions of this relationship. In-depth interviews were conducted with disabled people and family members in 4 rural areas (indigenous and non-indigenous) and thematic analysis was employed in the bid to find common themes and patterns in the data. The key findings and report prioritise and articulate the narratives of persons with disabilities.

5. Detailed Methodology

5.1 Population-based Survey

Key Messages in this section:

- **Study sample: Using probability proportionate to size sampling, 56 clusters of 50 people were selected in each of five regions covering all of Guatemala: Central, North-East, North-West, South-West and South-East (total sample size: 14,000)**
- **Survey teams completed a household roster at each eligible household, before screening each person for a disability using the Washington Group Extended Sets on Functioning**
- **Any participant reporting a significant functional limitation ("a lot of difficulty" or "cannot do") in any functional domain was considered to have a disability for the purposes of the study**
- **Any participant age 5+ who reported "some" or greater difficulty with seeing, hearing, walking or (18+) anxiety/depression also undertook a clinical screen in the corresponding domain. If they were identified to have a moderate or above impairment, they were also included in the disability estimates**

Sampling Strategy

For the purposes of the survey we divided the country into five broad geographical regions (Guatemala Central, North-East, North-West, South-West and South-East). Based on previous studies, we estimated that the all-age prevalence of disability in Guatemala would be 6%. This required a sample size of 2760 in each region giving a national sample size of 13,800, assuming precision of 20%, 95% confidence, a design effect of 1.5 and 15% non-response. This equated to 276 clusters of 50 people (rounded up to 56 per region).

We collaborated with the Guatemala Instituto Nacional de Estadistica (INE, the National Statistical Office of Guatemala) to select the survey sample. Multi-stage stratified cluster random sampling with probability proportional to size procedures was used to identify a nationally representative sample, using the most recent available Census data from INE as the sampling frame and stratifying by urban/rural and socio-economic status.

In each region we randomly selected 56 clusters. Within each cluster, we used compact segment sampling and INE cluster maps to divide the cluster into equal segments of approximately 50 people (10 households). One segment was then randomly selected. In the selected segment, guided by a community member, the survey team visited all selected households, door to door, until 50 people have been included. If the total of 50 people per cluster was reached within one household, all members of that household were still included in the survey meaning that some clusters included more than 50 people.

The compact segment sampling approach has been used in many previous health surveys rather than random walk method because a) it is logistically easier and b) it is also less subjective as the risk of survey teams being deliberately guided towards households known to have people with disabilities is reduced[9].

Data Collection

Where feasible, the survey team conducted enumeration one to two days in advance of the disability screening. Within each household the purpose of the survey was explained verbally to the household head or an adult key informant using a pre-written study information sheet, and permission to undertake the interview was sought.

For consenting households, all eligible household members were listed using a household roster. Eligible household members were defined as people who have lived in the household for at least six months of the last year. Demographic data (all ages: age, sex, ethnicity and adults: education, literacy and marital status were collected on household members. In addition, data on indicators of socio-economic status (SES) were recorded through question (ownership of assets) and observation (building materials of the house).

Disability measurement:

Disability status was first assessed for each household member aged 2+ years using the Washington Group Extended Set on Functioning for adults aged ≥18 years, and the UNICEF/WG Extended Set on Functioning for children aged 2-17 years (see appendix 1 for full modules). Children aged <2 years were excluded due to the lack of available survey tools to assess disability in this age group).

Using the latest recommendations from the WG[10], for the purposes of this study, disability was defined as reporting "significant" functional limitations, namely:

- Adults:
    - reporting "a lot of difficulty" or "cannot do" in seeing, hearing, walking, self-care, communication (understanding/being understood), cognition (remembering and concentrating), upper body (fine motor dexterity and upper body strength)
    - For anxiety and depression domains: reporting experience of anxiety/depression daily and at the level of 'a lot'
- Children:
    - Aged 2-4: Reporting "a lot of difficulty" or "cannot do" in seeing, hearing, walking, fine motor dexterity, understanding, being understood. learning, playing and controlling behaviour[2]
    - Aged 5-17: Reporting "a lot of difficulty" or "cannot do" in seeing, hearing, walking, self-care, understanding, being understood. learning, remembering, concentrating, accepting change, controlling behaviour, anxiety and depression[3]

[2] Controlling Behaviour response options are "not at all", "the same or less", "more" and "a lot more" compared to children of the same age. Response of "a lot more" was considered significant limitation

[3] Anxiety and Depression response options "daily", "weekly", "monthly", "a few times a year", "never".

These tools have been tested in a number of settings by the ICED research group, including Kenya, Cameroon and India.

For children under 10 years, questions were asked to a primary caregiver, in the presence of the child where possible. Children aged 10-17 years were interviewed directly in the presence of an adult caregiver. For any child aged 10-17 years or adult (18+years) who were unable to communicate independently, questions were asked to an adult caregiver as a proxy.

Clinical screens:

In addition, for each individual aged 5+ reporting "some" or greater difficulty in function related to vision, hearing and physical impairment, a simplified clinical screen was completed, using mobile data collection tools, to ascertain the presence and level of clinical impairment. For each individual aged 18+ reporting monthly or more frequent episodes of anxiety or depression, a clinical depression screen was also completed. This is based on previous findings that clinical screening amongst all participants reporting "some" or greater difficulty will identify approximately 95% of moderate or higher impairments in the population[11]. Participants who reported "some" difficulty and were determined to have a moderate or worse impairment in the corresponding domain, were presumed to have significant functional limitations and included in the prevalence estimate. See table 2 and figure s 5-7 below page for more details.

Photo 3: Testing for Hearing Impairment

Response of "daily" considered significant limitation

Table 2: Clinical Tools

	Measure	Thresholds	Assessment Application Details
Vision	Visual Acuity (presenting and pin hole)	Presenting vision in better eye: Moderate: VA<6/18 but ≥6/60 Severe: VA <6/60 but ≥3/60 Blind: VA<3/60	Portable Eye Examination Kit (PEEK) developed by LSHTM Jordan, Stewart, Hannah Kuper, and Matthew J. Burton. "Development and Validation of a Smartphone-Based Visual Acuity Test (Peek Acuity) for Clinical Practice and Community-Based Fieldwork." (2015).
Hearing	Pure Tone Audiometry	Audiometry in the better ear: Moderate: 41 – 60 dBa Severe: 61 – 80 dBa Profound: >80 dBa	HearTest, developed by the University of Pretoria, South Africa Swanepoel, De Wet, et al. "Smartphone hearing screening with integrated quality control and data management." International journal of audiology53.12 (2014): 841-849.
Physical	Physical Performance Test	Score (max 36) across 9 items Highest Tertile: 0-11 Middle Tertile: 12-21 Lowest Tertile: 22-32	Physical Functioning Assessment Tool Brown, M., et al., Physical and performance measures for the identification of mild to moderate frailty. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 2000. 55(6): p. M350-M355.
Depression	Patient Health Questionnaire (PHQ)-9	Score (max 27) across 9 items Moderate 10 -14 Moderately Severe 15-19 Severe 20-27	Patient Health Questionnaire, developed for use within the framework of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSIM-IV) Löwe, Bernd, et al. "Measuring depression outcome with a brief self-report instrument: sensitivity to change of the Patient Health Questionnaire (PHQ-9)." Journal of affective disorders 81.1 (2004): 61-66.

Overview of Disability Screening Protocols

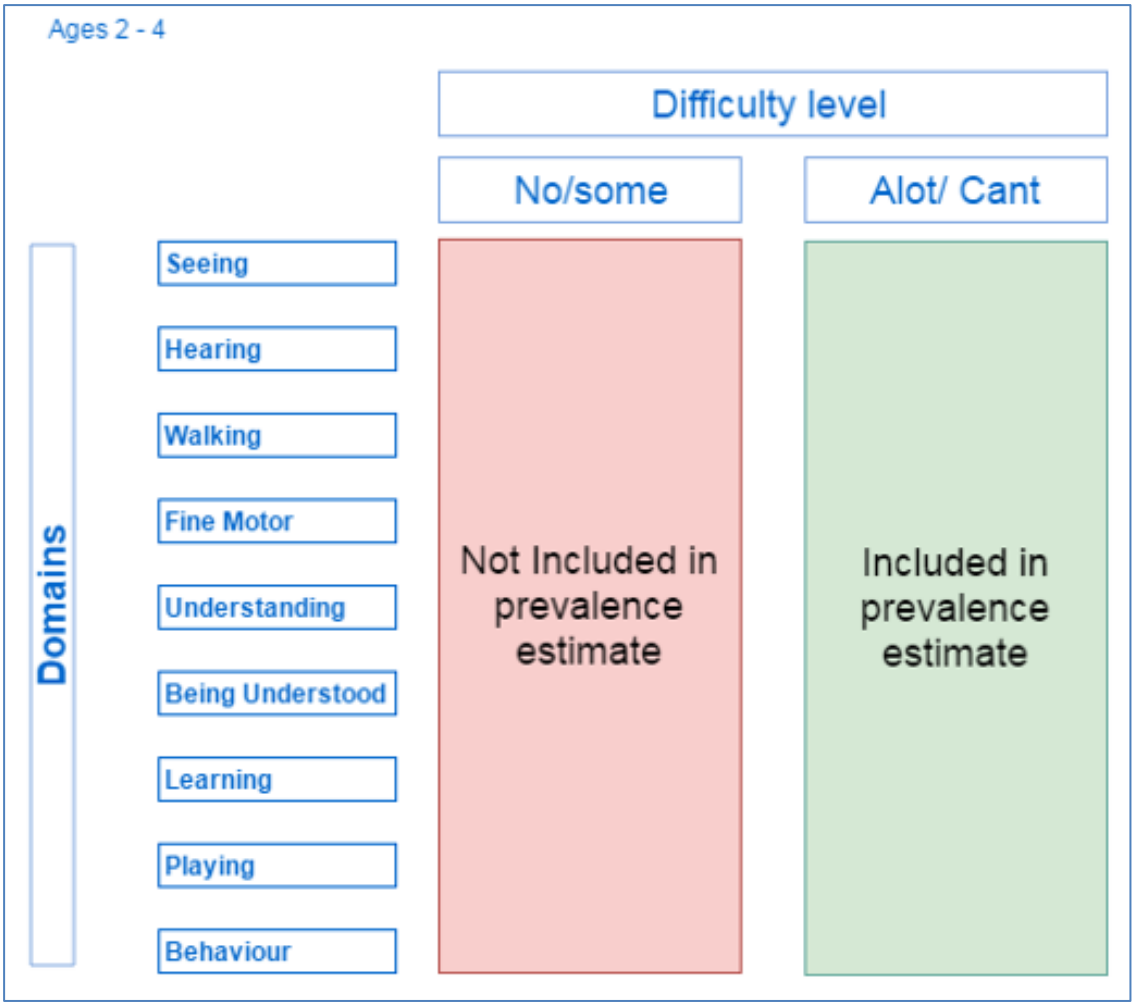


Figure 3: Screening Protocol Ages 2-4

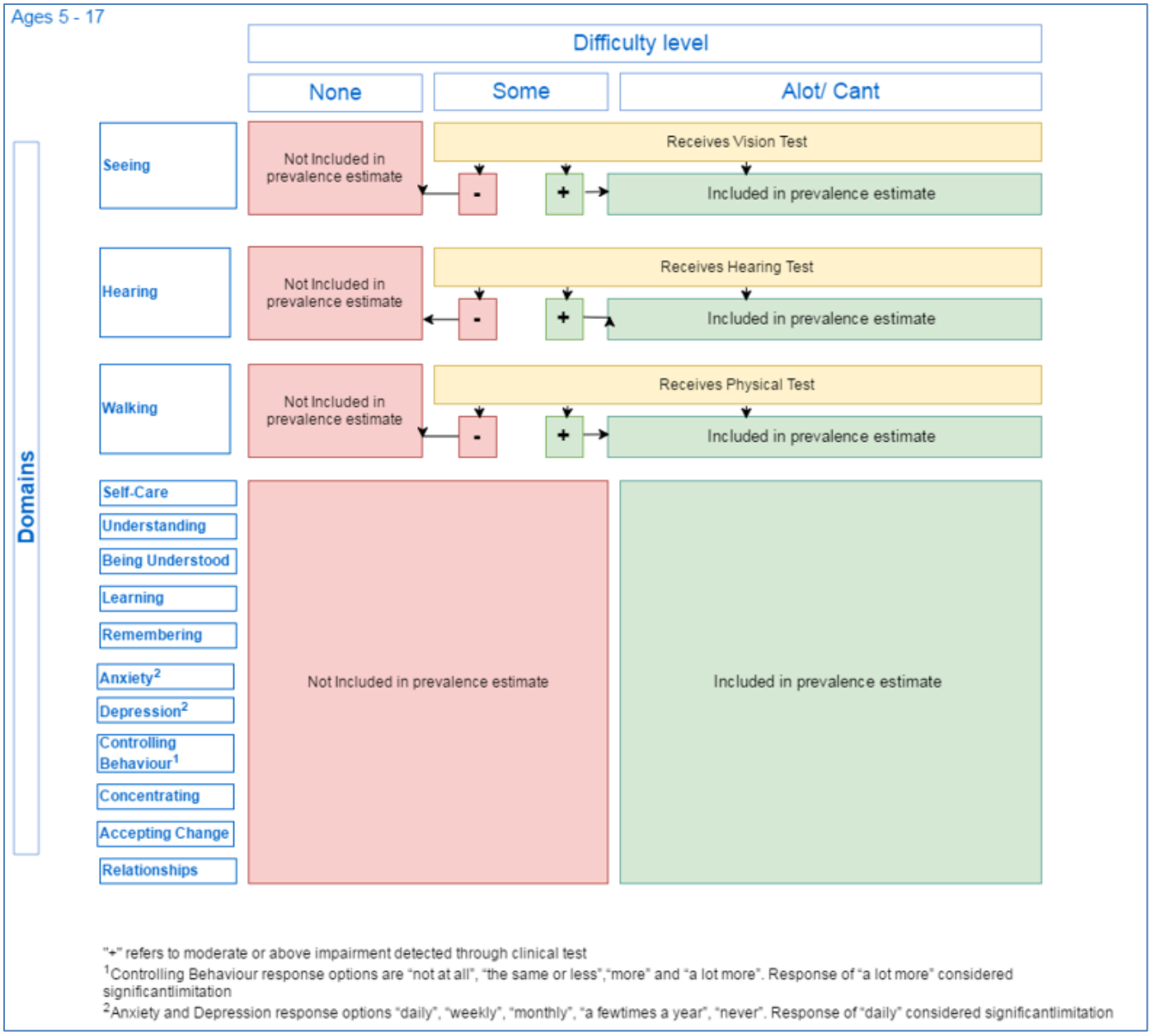


Figure 4: Screening Protocol Ages 5 - 17

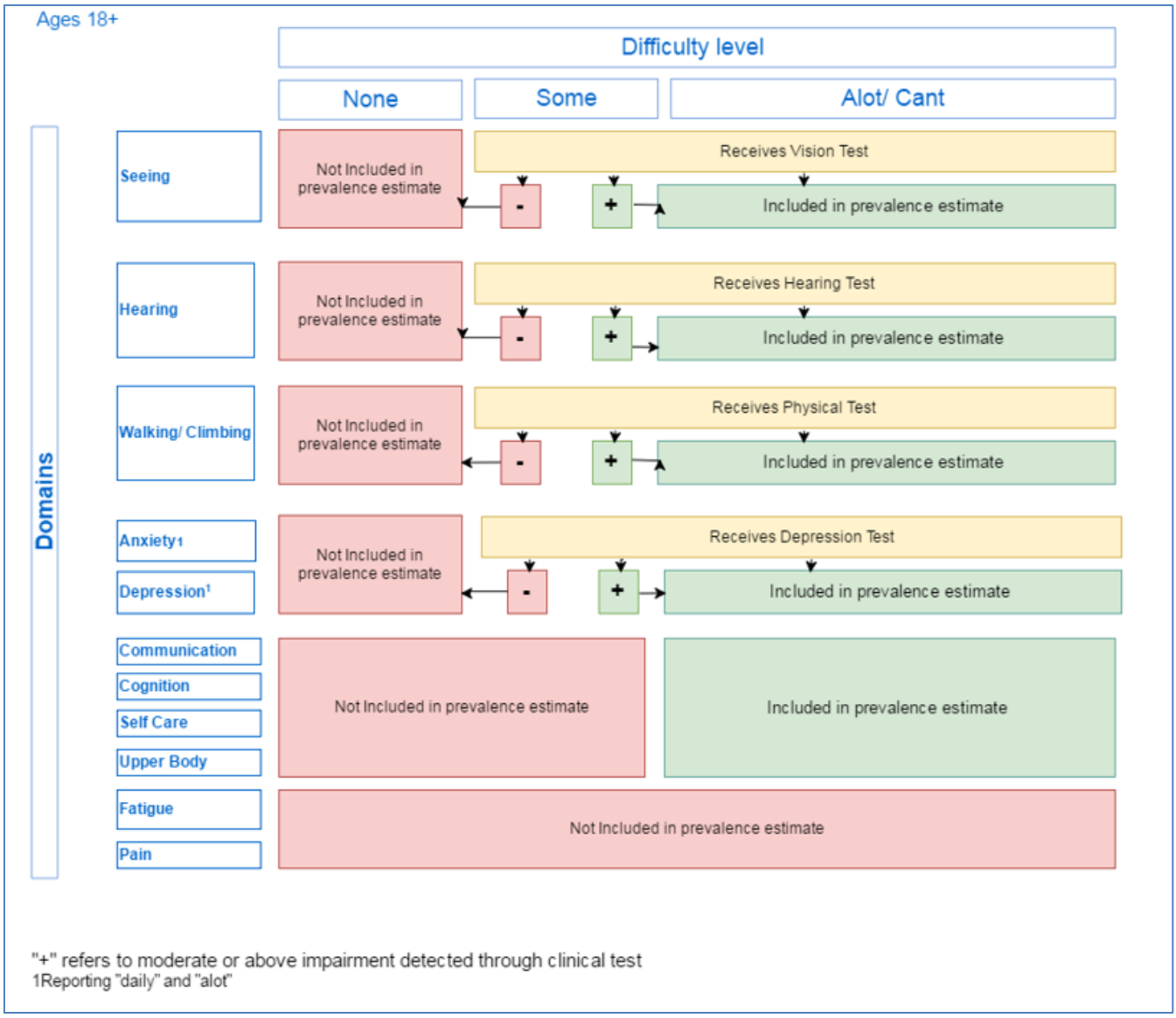


Figure 5: Screening Protocol Ages 18+

Non-respondents and refusals:

If eligible household members were not available for screening face-to-face, two repeat visits were made. Field teams worked on evenings and weekends as needed to minimise non-response. An additional fortnight was added to the data collection period at the end of the study to allow a final round of "Mop Up" in clusters where participants were previously unavailable.

Eligible people who were not available after two repeat visits to the household were recorded as non-responders.

If participants refused for themselves only this was recorded and no new participant was sought. If an entire household refused to participate, this was recorded and a replacement household was sought.

5.2 Nested Case Control Study

Key Messages in this section:

- **A "Nested Case-Control Study" compared people with disabilities ("cases") identified via the national survey, with age and sex matched community members without disabilities ("controls")**
- **People with and without disabilities (age 5+) were interviewed about education, livelihoods, health and antenatal care, water and sanitation, participation restrictions, environment, , quality of life, anthropometry and for people with disabilities only, rehabilitation**

In Public Health Research, a Case Control study refers to a methodology that compares participants with an outcome of interest ("cases") with participants who do not have the outcome of interest ("controls"). In this study, the outcome of interest is disability, therefore "cases" are people identified to have a disability during the National Survey, and "controls" are members of the same community matched to each person with a disability based on their sex and age-range.

For the purposes of this sub-study, the definition of 'disability' is reporting "a lot of difficulty" or "cannot do at all" in one of the core domains of the Washington Group question set: seeing, hearing, walking, self-care, understanding, being understood, learning, remembering, anxiety and depression. For each person identified as having a disability ("case") one age and sex matched "control" who did not fulfil the case criteria from within the same cluster. Controls were matched by sex and by age within +/-10 years for adults and +/- 2 years for children.

Components included in the case-control questionnaire were:

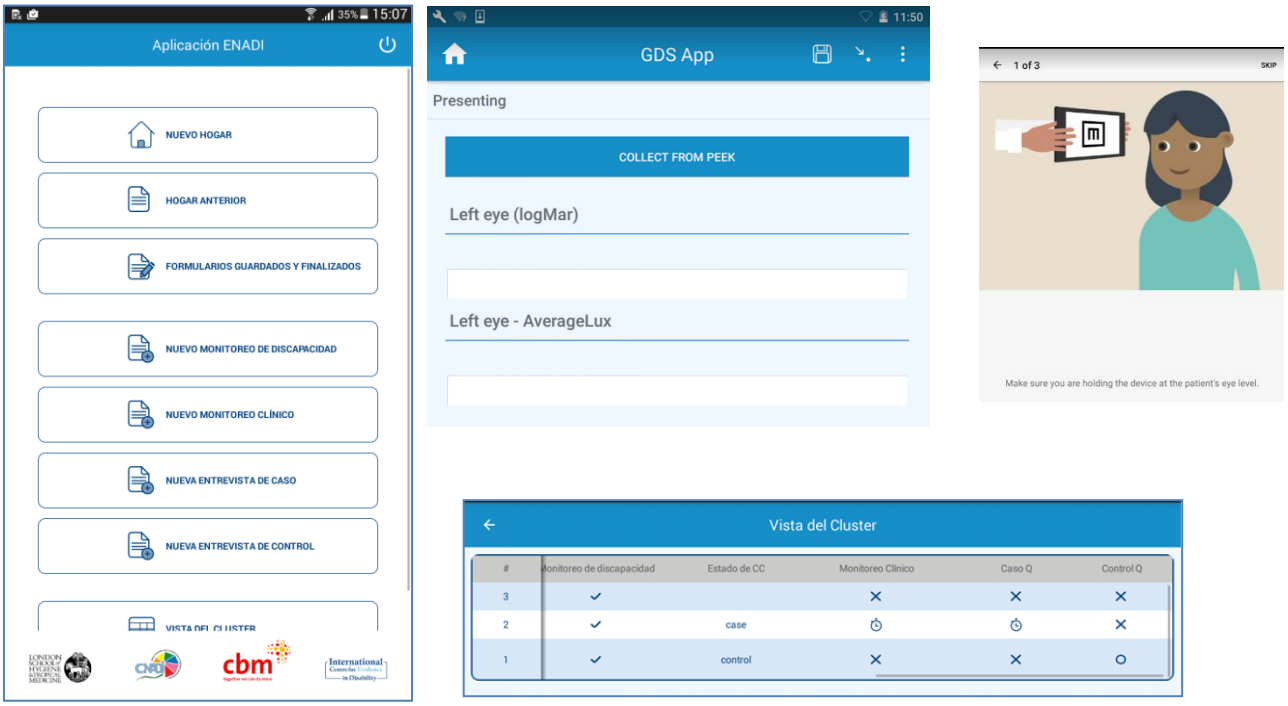
- Education
- Livelihoods
- Health and antenatal care
- Water and Sanitation

- Participation restrictions
- Environment
- Informal support networks
- Quality of life
- Anthropometry (height, weight, Middle Upper Arm Circumference (MUAC)
- Cases only: Rehabilitation

5.3 Mobile data entry

All survey (including clinical screening) and case control data were collected on an android tablet using a bespoke mobile application developed in collaboration with Universal Doctor Projects and Tools (UPT) for this survey (Photo 2). The use of mobile data entry minimises the risk of interviewer error through incorporating automatic consistency checks and skip patterns. It also allows immediate entry in the field and immediate, secure upload of the data to the database, negating the need for time-consuming manual data entry and dramatically decreasing the associated costs of this. Data can be viewed immediately following data collection and uploading, which also allows for regular monitoring of data quality. Data from the tablets was transferred daily via Wi-Fi to a secure, password-protected, cloud-based server.

Photo 4: Mobile Data Collection



5.4 Survey teams

Five survey teams, two comprising three interviewers and three comprising four interviewers were recruited for the study from a variety of backgrounds related to previous survey experience, previous community and disability experience and knowledge of Mayan languages.

Interviewers underwent a ten day training on all aspects of the project protocol and methods. This included:

- Purpose and overview of the survey
- Ethical considerations and responsibilities
- Cluster mapping and compact segment sampling
- Household eligibility
- Interview techniques, the importance of consistency and following protocols
- Questionnaire administration and form filling - step by step introduction to each question and response option
- Disability and impairment screening
- Extensive practice interviews among group and with target population
- Assessment of consistency in interviewing approach
- Practice data collection in pilot cluster

Photo 5: Survey Team

5.5 Qualitative Study

In-depth interviews were conducted with 27 disabled adults (14 men and 13 women) residing in rural areas whose ages ranged from 18 to 67. Five participants had intellectual impairments, 3 sensory and 19 had physical impairments. All participants self-identified as 'disabled' or a variant of this, and also as 'poor' or 'living in conditions of poverty'. Interviews were also conducted with 6 family members in an effort to triangulate and add detail. Interviews were largely held in participants' homes and in a small number of cases in the premises of the NGO acting as gatekeeper.

Most interviews were held directly in Spanish. In a small number of cases, a translator/cultural mediator was used with indigenous participants who do not speak Spanish. While these were not professionally trained translators, they had experience translating for organisational and other personnel. They are also well known and trusted by participants. Interviews were recorded using a digital voice recorder and later transcribed verbatim.

The executive findings from this study are presented later in this document, and the report is available at: *http://disabilitycentre.lshtm.ac.uk.*

5.6 Ethics

Ethical approval for the study was provided by:

- The London School of Hygiene & Tropical Medicine (LSHTM)
- The Comité de Ética Independiente en Investigación (Latin Ethics), Guatemala

Informed written consent (signature or thumb print if illiterate) was sought from all household heads prior to enumeration and all participants in the qualitative study. Informed written consent was sought from all participants in the population-based survey and nested case-control.

All participants under the age of 18 had a caregiver or guardian present throughout the interview process. Participants <18 were asked for verbal assent. For adults and children unable to communicate, the individual's carer or guardian answered as a proxy. Any individuals feeling uncomfortable about participation were excluded from the study without pressure.

A National Directory of Disability Services was completed with support from ASCATED and CONADI, and distributed to the nearest health centre to each of the study clusters. Participants expressing desire for services in relation to disability were advised to visit their nearest health centre.

Qualitative Interviews were recorded using a digital voice recorder following permission by the participants, and then transcribed.

5.7 Language

Interviewers were selected with the dominant Mayan languages (Mam, K'iche', Kaqchikel, and Q'eqchi) in mind. The Washington Group Questions were then translated into each of the four Mayan languages to ensure consistency as much as possible. In areas where different dialects of the dominant languages, or minor Mayan languages, were spoken, interviewers sought assistance first from a

member of the family, or from a local school teacher, to provide verbal translation between Spanish and the participant's language of choice.

5.8 Data Analysis

Data analysis was completed using the statistical package STATA. We used the SVY command in Stata to take into account the survey design. Disability prevalence estimates (with 95% confidence intervals) were calculated disaggregated by age, sex, region and urban/rural location. Mutually exclusive proportions were rounded up to the nearest whole integer, so may not add up to exactly 100%.

We constructed a socio-economic status (SES) score using principal component analysis (PCA) of household asset ownership and household building materials. This SES score was then divided into quintiles.

Within the case-control study, 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[12]. 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". Sub-scale scores were converted into scores out of 100 for ease of interpretation with lower scores denoting greater participation restrictions.

Environment scores were also generated using a SINTEF question set which includes 12 questions on the frequency at which elements of the built and natural environment created barriers were also asked to both cases and controls. Response categories for each question were 1- Daily, 2- Weekly, 3- Monthly, 4- Less than Monthly, 5-Never, 6-Not Applicable.

Quality of life was measured using the WHO Quality of life-BREF instrument[13]. This includes 26 questions across four domains: physical health, psychological health, social relationships and the environment. Questions are measured using a five-point response scale. Sub-scale scores were converted into scores out of 100, for ease of interpretation, with higher scores denoting greater quality of life.

Multivariable logistic regression analysis was used to identify differences between a) households with and without people with disabilities in demographic and socio-economic characteristics and b) people with and without disabilities, including children, in the domains of education, economic activity, water and sanitation, health and participation and activities, support mechanisms and access to services. These analyses were adjusted for age, sex, region and socio-economic status (SES) due to these being likely confounding factors. We conducted logistic regression to generate Odds Ratios and 95% Confidence Intervals which are explained in the box below).

Linear regression analyses were generated to compare the quality of life, participation and environment scores of people with disability to children without disability adjusted for age, sex, region and SES.

Factors associated with inclusion among people with disabilities

We also used regression analysis to explore, among people with disabilities, the association between indicators of inclusion (school attendance, work status, quality of sanitation access, use of health services, participation and QoL) and socio-demographic characteristics (age, sex, SES, urban/rural location, region education, marital status) and type of significant functional limitations.

Understanding Odds Ratios:

An odds ratio (OR) is a measure of the association between an exposure and an outcome. In this example, between household poverty (exposure) and whether the person has a disability (outcome). The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure. An OR of suggests no association between the exposure and outcome. An OR>1 suggests the exposure is associated with a higher odds of the outcome occurring. An OR <1 suggests the exposure is associated with a lower odds of the outcome occurring

The 95% confidence interval shows the range of odds ratios that are likely, with 95% probability. If the confidence interval does not include 1, then the odds ratio is statistically significant (as in the example given above). Confidence intervals are also shown around estimates of prevalence, indicating the range within which we can be 95% sure that the true population estimate exists.

As an example:

- Odds of disability for a person living in poorest household group= 250/262=0.95.
- Odds of disability for a person living in wealthiest household group = 46/26=1.77
- Odds ratio = 1.77/0.95 = 1.9, 95% confidence interval 1.1 – 3.1).

This means that people living in the poorest households are almost twice as likely to have a disability compared to those living in the wealthiest households, and that this result is statistically significant at the 95% confidence interval.

Additional Technical Terms:

- Prevalence: Measurement of all individuals with the condition of interest at a particular point in time
- Dependency Ratio: The ratio of the number of dependents (aged less than 15 or greater than 65 years old) to independents (aged between 15-64 years old) living in the household
- Confounding: Distortion in measure of association between two variables caused by a third (or more) variable
- Logistic Regression: Statistical method for assessing the association between two variables, allowing adjustment for confounding
- P-Value: Probability that the result is significant (see “Statistical Significance” below).
- Response rate: Proportion of participants who completed the survey out of the total number of participants in the sample size calculation

- Statistical Significance: Results that are highly likely at a pre-set level of confidence (in this study with 95% confidence) not to have resulted from chance

5.9 Dissemination

Dissemination activities for the survey took place in early March 2017. These included workshops with four targeted audiences in Guatemala City:

- Representatives from Guatemala Disabled People's Organisations
- CONADI's technical team and extended partners
- International Organisations
- Policy makers, government representatives and the press – facilitated by the President of the Guatemala Congress on Disability

In addition, department-level dissemination workshops were coordinated by CONADI to take place in late March 2017.

6. Results

6.1 Findings from the national survey

Key Messages in this section:

- **13,073 people participated in the survey (a response rate of 88%)**
- **The age and sex distribution of the sample closely matched the national population estimates**
- **All age disability prevalence was 10.2% (95% CI 9.3 – 11.2).**
- **Disability prevalence increased by age and was 24.1% (21.9 – 26.5) among adults aged over 50 years.**
- **Among adults, prevalence of disability was higher for women compared to men.**
- **There were regional differences in estimated prevalence with the highest prevalence in Central and North West and lowest in North East and South East.**
- **Among adults, the prevalence of significant limitations was highest in the domains of anxiety/depression (9.3%) mobility (8.0%), seeing (4.2%) and hearing (4.0%).**
- **Among children, the prevalence of significant limitations was highest in the domains of anxiety (1.9%), mobility (1.0%) and maintaining relationships (1.0%).**

Study population

The overall response rate was good with a total of 13,073 out of 14,873[4] eligible people participing in the survey (88%). A further 251 people refused (2%) and 1548 were unavailable (10%) The response rate was lowest in Central region (75%) and was between 89-92% for the other four regions. The age and sex distribution of the sample population closely reflected that of the national population according to the latest available estimates (Table 3). Achieving this overall good response rate and a similar age and sex distribution to the national population was important for ensuring a representative sample and limiting the role of selection bias

[4] The sample size was calculated to include 276 clusters of 50 people. In practise, when we reached the last household in a cluster with the 50th person, we included all household members in that house. This means that some clusters had more than 50 people, explaining why the total number of eligible participants was greater than the initial sample size calculation.

Table 3: Age and sex distribution of the national population and study sample

	Male		Female		Total	
Age group	National	Sample	National	Sample	National	Sample
0-14 years	2711683 (36%)	2216 (37%)	2608295 (34%)	2220 (31%)	5,319,978 (35%)	4,146 (34%)
15-24 years	1663484 (22%)	1323 (22%)	1647749 (21%)	1582 (22%)	3,311,233 (22%)	2,905 (22%)
25-54 years	2425931 (32%)	1772 (29%)	2666790 (35%)	2435 (35%)	5,092,721 (34%)	4,208 (32%)
55-64 years	377,672 (5%)	325 (5%)	416,939 (5%)	413 (6%)	794,611 (5%)	738 (6%)
65+ years	311,165 (4%)	397 (6%)	360,280 (5%)	409 (6%)	671,445 (4%)	806 (6%)
Total	7489935 (49%)	6033 (46%)	7700053 (51%)	7,039 (54%)	15189988	13,073

*Data on sex missing for 1 person; Source of national estimates: CIA world Factobook, 2016

Prevalence of disability

A total of 1,331 people were classified as having a disability according to the study definition using the WG questions with the additional inclusion of clinical screens. All those reporting a significant functional limitation ("a lot of difficulty" or "cannot do") in any core domain, or identified to have a significant clinical impairment (moderate or above) are included in this estimate, giving an all-age prevalence estimate of 10.2% (95% CI 9.3 – 11.2) – Table 4. The prevalence increased with increasing age from 5.3 (95% CI 4.5 - 6.1) among children to 24.1% (21.9 – 26.5) among adults aged >50 years. The overall prevalence was significantly higher among women 11.8 (10.7 – 13.0) compared to men 8.3 (7.4 – 9.3).

Table 4:Prevalence of disability by age and sex

	Prevalence (95% CI)			
Age group	2-17 years n=5,469	18-49 years n=5,569	50+ years n=2,035	All ages n= 13,072
Sex				
Male (n=6,033)	4.9 (4.0 – 5.9)	6.9 (5.7 – 8.3)	21.5 (18.9 - 24.3)	8.3 (7.4 – 9.3)
Female (n=7,039)	5.7 (4.8 – 6.8)	12.1 (10.7 – 13.6) [a]	26.3 (23.4 – 29.4) [a]	11.8 (10.7 – 13.0) [a]
All (n= 13,072)	5.3% (4.5 - 6.1)	9.9% (8.8 – 11.1)	24.1% (21.9 – 26.5)	10.2% (9.3 – 11.2)

[a] Significant difference in prevalence by sex (p<0.05)

Prevalence estimates varied by region and was highest among the Central (15.7%, 13.4 – 18.2) and North West regions (14.9%, 12.6 – 17.5) and lowest in the North East (6.1%, 5.0 – 7.4) and South East (5.4%, 4.5 – 6.5), overall and when stratified by age group and sex (table 5 and 6). Similar age and sex trends in prevalence were also observed within each region separately (Table 6).

Table 5: Prevalence of disability by region and urban/rural location

	Total	No with disability	Prevalence (95% CI)
Region			
Central	2201	345	15.7 (13.4 – 18.2)
North East	2740	166	6.1 (5.0 – 7.4)
North West	2643	394	14.9 (12.6 – 17.5)
South East	2837	152	5.4 (4.5 – 6.5)
South West	2652	274	10.4 (8.8 – 12.2)
Location			
Rural	8039	727	9.1 (8.0 – 10.3)
Urban	5034	604	12.0 (10.6 – 13.4)

Table 6: Age and sex specific prevalence estimates of disability by region

	Central N=2201	North East N=2740	North West N=2643	South East N=2837	South West N=2652
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Age group					
2-17 years	8.8% (6.7-11.7)	2.8% (1.9-4.3)	8.3% (0.6-10.7)	2.2% (1.4-3.4)	5.3% (4.0-6.9)
18-49 years	15.9% (12.7-18.9)	5.2% (3.7-7.5)	15.1% (12.2-18.5)	5.0% (3.8-6.6)	9.7% (7.7-12.1)
50+ years	30.3% (24.8– 36.4)	18.1% (14.5-22.4)	36.9% (31.5-42.5)	14.5% (11.5-18.2)	23.7% (19.3-28.7)
Sex					
Male	11.1% (0.9-13.9)	5.0% (0.9-13.9)	13.8% (11.3-16.7)	4.3% (3.2-5.6)	8.2% (10.3-14.5)
Female	19.3% (16.6-22.4)	7.0% (5.5-8.8)	15.8% (13.2-18.9)	6.3% (5.1-7.9)	12.2% (10.3-14.5)
Total	15.7 (13.4-18.2)	6.1 (5.0-7.4)	14.9% (12.6-17.5)	5.4% (4.5-6.5)	10.4% (8.8-12.2)

Prevalence by functional domain

This section breaks down the combined prevalence estimate of disability by functyional domain. Table 7 reports the proportion of adults aged ≥18 years with experiencing significant limitations in each domain. These proportions are not mutually exclusive, with 44% of adults with disabilities experiencing significant limitations in more than one domain. The most common significant limitations amongst adults were in anxiety/depression (9.3%, 8.4 – 10.3), mobility (8.0%, 7.1 – 9.1), and seeing (4.2%, 3.7 – 4.8). Prevalence increased with age across all domains (graph 1), and was significantly higher in women than men for anxiety/depression and mobility.

There was substantial overlap amongst the proportion of adults reporting anxiety or depression, of whom 21% reported both, 68% reported symptoms of depression only and 11% reported symptoms of anxiety only.

Table 7: Prevalence by domain in adults age 18+

	Total (n=7,603)		Male (n=3270)		Female (n= 4,333)	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Seeing[a]	322	4.2 (3.7 – 4.8)	128	3.9 (3.2 – 4.7)	194	4.4 (3.8 – 5.2)
Hearing[a]	301	4.0 (3.5 – 4.5)	142	4.3 (3.7 – 5.2)	159	3.7 (3.1 – 4.3)
Mobility[a]	610	8.0 (7.1 – 9.1)	214	6.5 (5.6 – 7.7)	396	9.1 (8.0 – 10.5)[b]
Anxiety/Depression[a]	705	9.3 (8.4 – 10.3)	193	5.9 (5.0 – 7.0)	512	11.8 (10.6 – 13.1) [b]
Self-care	88	1.2 (0.9 – 1.4)	36	1.1 (0.8 – 1.5)	52	1.2 (0.9 - 1.6)
Communicating	65	0.9 (0.6 – 1.2)	26	0.8 (0.5 – 1.3)	39	0.9 (0.5 – 1.3)
Upper body strength	134	1.8 (1.4 – 2.2)	51	1.5 (1.2 – 2.1)	83	1.9 (1.5 – 2.4)
Cognition	177	2.3 (1.9 – 2.8)	55	1.7 (1.2 – 2.3)	122	2.8 (2.3 – 3.4)
[a]Includes both significant reported functional limitation and/or significant clinical impairment						

[b] Significant difference in prevalence by sex (p<0.05)

Regional prevalence by domain

Region-wise proportions of the most commonly reported limitations amongst adults are reported in table 8. Prevalence ranged between 4.1 – 7.1% for anxiety/depression, 1.9 – 7.2% for mobility, 1.1 – 3.7% for vision, and 1.5 – 3.1% for hearing.

Table 8: Regional prevalence for the most common significant functional limitations in adults

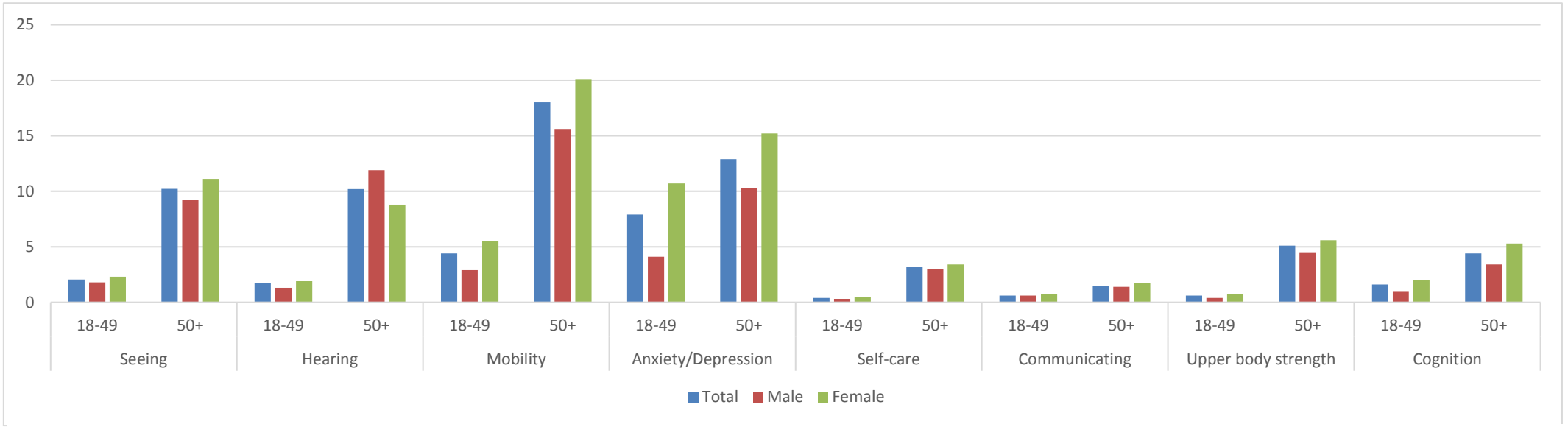
	Region				
	Central N=2201	North East N=2740	North West N=2643	South East N=2837	South West N=2652
Anxiety/Depression	6.6 (5.4 – 7.8)	4.2 (3.4 – 5.2)	7.1 (5.7 – 8.8)	4.1 (3.2 – 5.2)	5.6 (4.5 – 6.9)
Mobility	7.2 (5.8 – 8.8)	2.2 (1.7 – 2.8)	6.4 (5.0 – 8.3)	1.9 (1.3 – 2.6)	4.9 (3.8 – 6.4)
Vision	3.2 (2.5 – 4.0)	1.3 (1.0 – 1.9)	3.7 (2.9 – 4.7)	1.1 (0.8 – 1.6)	2.5 (1.9 – 3.2)
Hearing	2.2 (1.6 – 2.8)	1.5 (1.1 – 2.2)	3.1 (2.4 -4.0)	2.2 (1.7 – 2.8)	2.3 (1.8 – 2.9)

Table 9 and graph 2 describe prevalence of disability by domain amongst children. The most common domains in which children experienced significant limitations were in anxiety/depression (2.5%, 2.0 – 3.1), maintaining relationships (1.0%, 0.8 – 1.4) and mobility (1.0%m 0.8 - 1.4). There were no differences by sex in any domain.

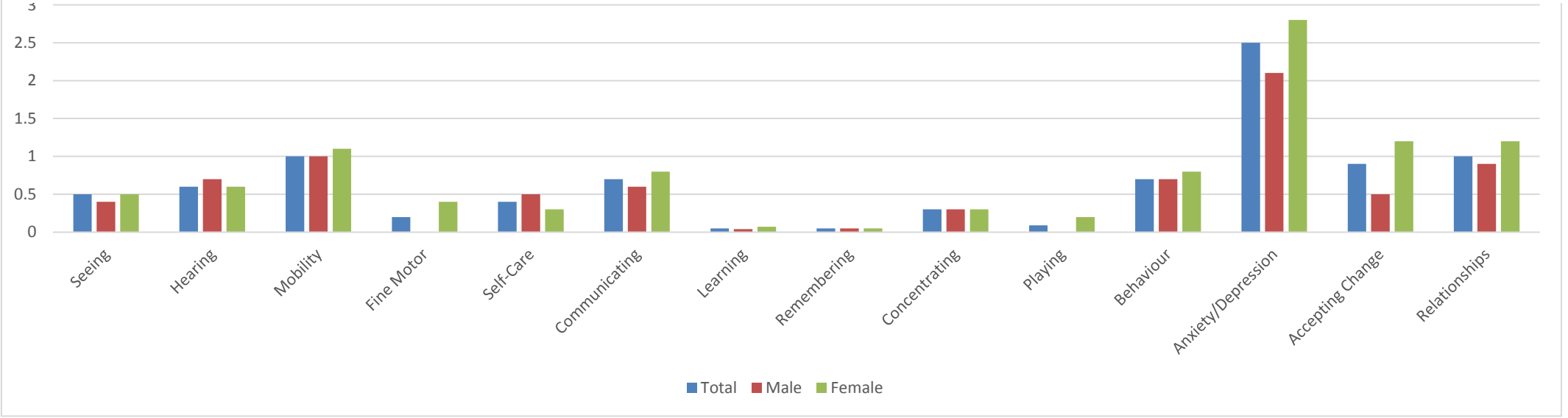
Table 9: Prevalence by domain in children aged 2-17

	Total (n=5,469)		Male (n=2,763)		Female (n=2,706)	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Seeing[a]	26	0.5 (0.3 – 0.7)	12	0.4 (0.2 – 0.8)	14	0.5 (0.3 – 0.9)
Hearing[a]	35	0.6 (0.5 – 0.9)	19	0.7 (0.4 – 1.1)	16	0.6 (0.4 – 1.0)
Mobility[a]	57	1.0 (0.8 – 1.4)	27	1.0 (0.6 – 1.5)	30	1.1 (0.8 – 1.6)
Fine Motor[b]	2	0.2 (0.05 – 0.8))	0	-	2	0.4 (0.1 – 1.5)
Self-Care[c]	16	0.4 (0.2 – 0.6)	10	0.5 (0.2 – 0.8)	6	0.3 (0.1 – 0.6)
Communicating	38	0.7 (0.5 – 1.0)	16	0.6 (0.3 – 1.0)	22	0.8 (0.5 – 1.3)
Learning	3	0.05 (0.02 – 0.2)	1	0.04 (0.01 – 0.3)	2	0.07 (0.01 – 0.3)
Remembering[c]	2	0.05 (0.01 – 0.2)	1	0.05 (0.01 – 0.3)	1	0.05 (0.01 – 0.3)
Concentrating[c]	12	0.3 (0.2 – 0.5)	6	0.3 (0.1 – 0.6)	6	0.3 (0.1 – 0.6)
Playing[b]	1	0.09 (0.01 – 0.7)	0	-	1	0.2 (0.03 – 1.4)
Behaviour	39	0.7 (0.5 – 1.0)	18	0.7 (0.4 – 1.0)	21	0.8 (0.5 – 1.2)
Anxiety/Depression[c]	109	2.5 (2.0 – 3.1)	47	2.1 (1.6 – 2.9)	62	2.8 (2.1 – 3.8)
Accepting Change[c]	38	0.9 (0.6 – 1.2)	12	0.5 (0.3 – 1.1)	26	1.2 (0.8 – 1.8)
Relationships[c]	46	1.0 (0.8 – 1.4)	20	0.9 (0.6 – 1.4)	26	1.2 (0.8 – 1.7)

[a]Amongst ages 5-17:Includes both significant reported functional limitation and/or significant clinical impairment
[b]Children 2 – 4 only
[c]Children 5 - 17 only



Graph 1: Prevalence by domain in adults by sex



Graph 2: Prevalence by domain in children by sex

Washington Group Functioning Domains

Key Messages in this section:

- **50% of adults reported at least "some" difficulty in at least one of the Washington Group domains, 7% reported "a lot" of difficulty in at least one domain and 4% reported "cannot do" in at least one domain.**
- **55% of children were reported to have at least some difficulty in at least one domain, 7% to have a lot" of difficulty in at least one domain and 6% to have the highest level of difficulty in at least one domain.**
- **The proportion of adults (46-54%) and children (49-64%) reporting "some" in at least one of the WG domains was similar in the five regions.**
- **Among adults, the domains with the highest proportion reporting "some" problem were cognition (30%), anxiety/depression (26%) and seeing (23%)**
- **The most common domains in which children were reported to have at least some difficulty were anxiety/depression (40.6%), controlling behaviour (27%) and remembering (20.9%).**
- **Overall, using the Washington Group Questions only, the all-age prevalence of disability would be 7.4%, the prevalence in adults 18+ would be 9.3% and the prevalence in children 2-17 would be 4.7%**

This section includes the findings using the Washington Group tools only (i.e. not the clinical screens).

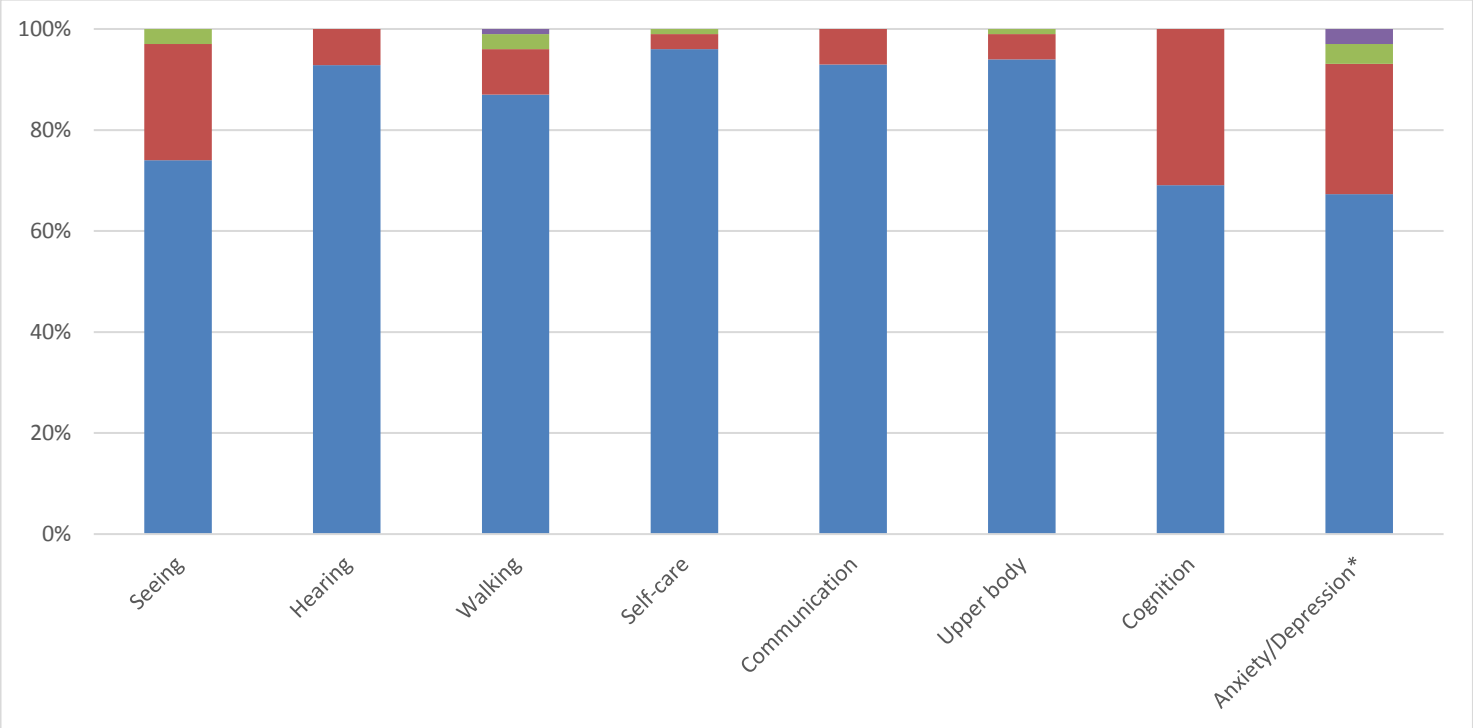
Table 10 shows the overall Washington Group response distributions for adults across all domains. Half of adults reported at least some difficulty in at least one domain, 7% reported "a lot" of difficulty in at least one domain and 4% reported "cannot do" in at least one domain. Response distributions were statistically different between men and women, by age group, by region and by location (urban/rural).

Overall, this means that 9.3% of adults age 18+ (95% CI 8.3 – 10.5) reported "a lot" of difficulty or "cannot do" in one or more core Washington Group domain. The all-age prevalence of disability using only the Washignton Group tools would be 9.3%, the prevalence in children 2-17 would be 4.7%, in adults 18 – 49 6.2% and in adults 50+ 17.7%. These numbers should be used when comparing the findings with other studies using the Washington Group tools only.

Graph 3 shows the response distribution in adults by domain. The anxiety/depression indicator includes four categories from Level 1 (low) to Level 4 (high), reflecting a combined score based on frequency and intensity of feelings. Among adults (table 4.4), the domains with the highest proportion reporting "some" problem were seeing (23%), anxiety/depression (26%) and cognition (30%).

Table 10: Washingtonn Group Response distribution among adults (18+)

	None	Some	A lot	Cannot do	P Value*
At least one domain (total)	39%	50%	7%	4%	-
Sex					
Male	46%	46%	6%	3%	<0.001
Female	34%	53%	8%	5%	
Age					
18 – 49	45%	47%	5%	3%	<0.001
50+	23%	57%	13%	7%	
Region					
Central	36%	46%	12%	7%	
North East	40%	54%	4%	2%	
North West	36%	47%	11%	6%	<0.001
South East	46%	49%	3%	2%	
South West	37%	51%	8%	3%	
Location					
Rural	40%	50%	7%	4%	<0.05
Urban	38%	49%	8%	5%	
*Results from Pearson's Chi^2 test of independence					



Graph 3: Washington Group Responses amongst adults per domain

*Anxiety/Depression 4-level indicator (i.e. reporting experiencing "daily" and at level of "a lot")

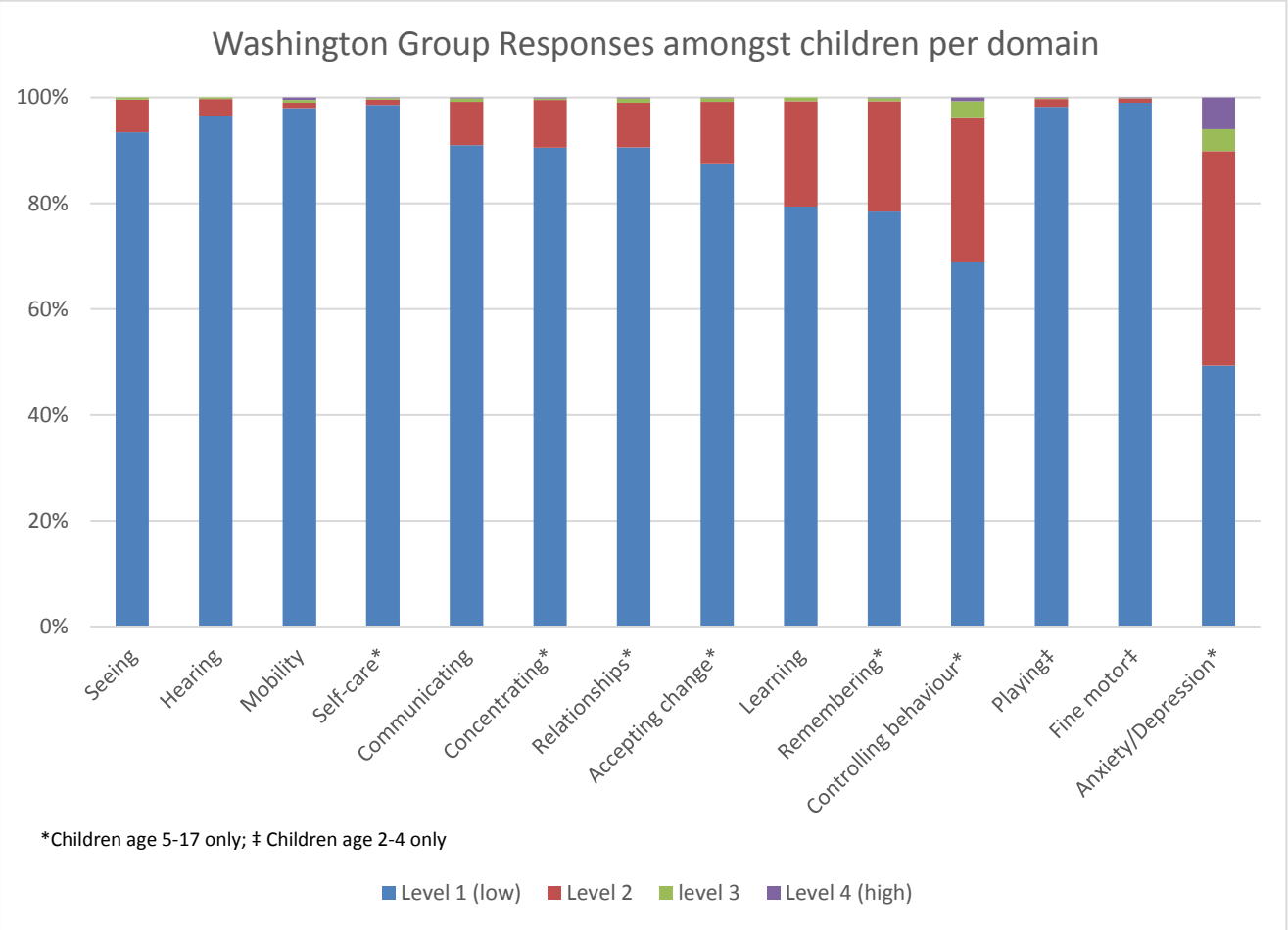
Among children (table 11), response categories were grouped as follows:

- Level 1 (lowest): reporting “none”, “not at all” or “never” across all domains
- Level 2: reporting “some”, “same or less” or “few times per year” in at least one domain
- Level 3: reporting “a lot”, “more” or “monthly” in at least one domain
- Level 4 (highest): reporting “Cannot Do”, “A lot More” or “Weekly or Daily” in at least on domain

Table 11 reports the overall Washington Group response distribution amongst children using the above groupings. Nearly a third (32%) of children were not reported to have any level of difficulty with any domain (Level 1), 55% were reported to have some difficulty in at least one domain, 7% to have a lot of difficulty in at least one domain and 6% to have the maximum level of difficulty in any domain. The most common domains in which children were reported to have at least some difficulty were anxiety/depression (40.6%), controlling behaviour (27%) and remembering (20.9%). There were no differences by sex, but response distributions varied significantly by age group, region and urban/rural location. Overall, 4.7% of children aged 2- 17 (95% CI 4.0 – 5.4) were reported to have “a lot” of difficulty or “cannot do” in one or more core Washington Group domain. This proportion should be used when comparing the findings with other studies of childhood disability using the Washington Group tools only. Similarly, the overall all-age estimate age 2+ using the Washington Group tools only is 7.4% (6.6 – 8.2).

Table 11: Washington Group response distribution amongst children

	None	Some	A lot	Cannot do	P Value*
At least one domain (total)	**32%**	**55%**	**7%**	**6%**	-
Sex					
Male	32%	56%	8%	5%	0.7
Female	32%	54%	7%	6%	
Age					
2-4	48%	44%	7%	1%	<0.001
5-17	28%	57%	8%	7%	
Region					
Central	28%	56%	8%	8%	
North East	34%	55%	7%	4%	
North West	34%	49%	9%	7%	<0.001
South East	39%	51%	6%	3%	
South West	22%	64%	7%	6%	
Location					
Rural	35%	54%	7%	5%	<0.001
Urban	27%	57%	8%	7%	
*Results from Pearson’s Chi^2 test of independence					



Graph 4: Washington Group Responses amongst children per domain

Clinical screening findings

Key Messages in this section:

- **4,293 people reported having at least "some" difficulty in either seeing, hearing, walking, anxiety or depression, and required the corresponding clinical screen**
- **8.4% of participants screened positive to one or more moderate or worse impairment (seeing, hearing, physical or depression)**
- **Due to missing data, extrapolations were made based on the patterns of the observed data**
- **1.0% of participants screened positive (i.e were found to have) visual impairment, 2.4% for hearing impairment 6.8% for physical impairment and 8.0% for depression**

A total of 4,293 people reported having some or greater difficulty in at least one of seeing, hearing, walking and anxiety and depression, therefore requiring a clinical examination in the corresponding

domain. Despite considerable efforts in training, data monitoring and revisiting clusters to collect missing data, clinical screening data were missing for 8% for vision, 13% for hearing, 26% for physical and 6% for depression triggers. We have therefore extrapolated the findings based on the patterns of the observed data to estimate the prevalence of impairments amongst both those screened and those with missing data (see table below).

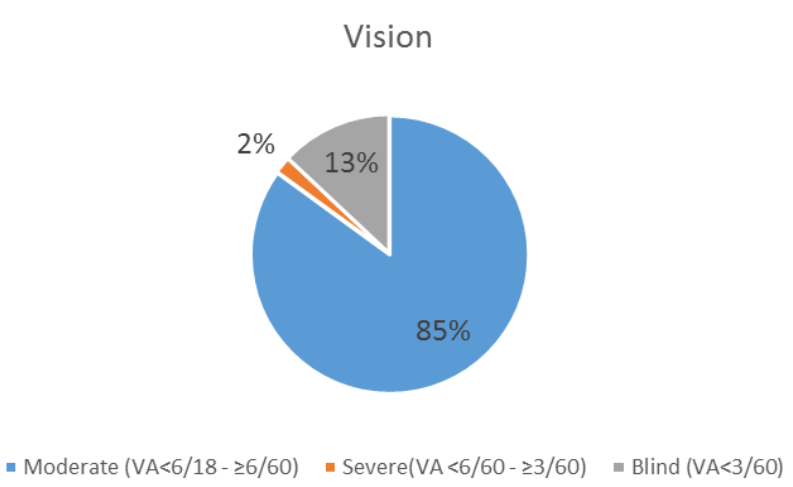
Table 12 shows the extrapolated prevalence estimates for all those who reported some or greater difficulty in the corresponding WG domain.

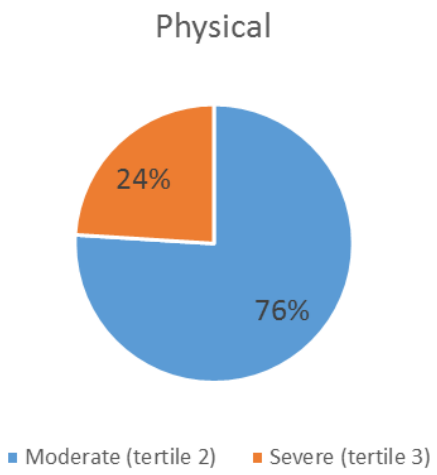
Table 12: Extrapolated clinical prevalence estimates

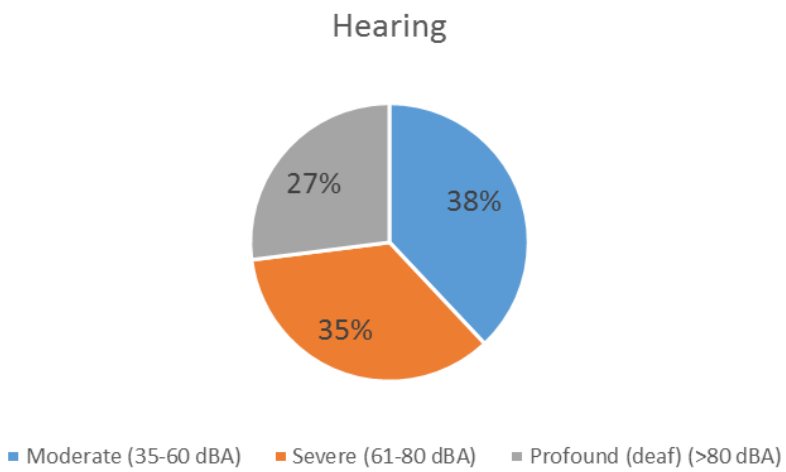
	All ages		5-17 years		18-49 years		50+ years	
	n	%	n	%	n	%	n	%
Any clinical impairment	1251	8.4%	65	1.5%	603	10.8%	580	28.5%
Male	418	6.0%	31	1.4%	154	6.6%	232	24.6%
Female	833	10.9%	34	1.6%	449	13.9%	348	31.9%
By impairment type								
Total vision impairment	131	1.0%	2	0.0%	35	0.6%	94	4.6%
Male	55	0.9%	1	0.0%	16	0.7%	38	4.0%
Female	76	1.1%	1	0.0%	19	0.6%	56	5.1%
Total hearing impairment	319	2.4%	26	0.6%	78	1.4%	215	10.6%
Male	155	2.6%	13	0.6%	27	1.2%	115	12.2%
Female	164	2.3%	13	0.6%	51	1.6%	100	9.2%
Total Physical Impairment	893	6.8%	42	1.0%	379	6.8%	472	23.2%
Male	311	5.2%	21	1.0%	105	4.5%	185	19.6%
Female	582	8.3%	21	1.0%	274	8.5%	287	26.3%
Total Depression	611	8.0%	-		381	6.8%	230	11.3%
Male	165	5.0%	-		77	3.3%	88	9.3%
Female	446	10.3%	-		304	9.4%	142	13.0%

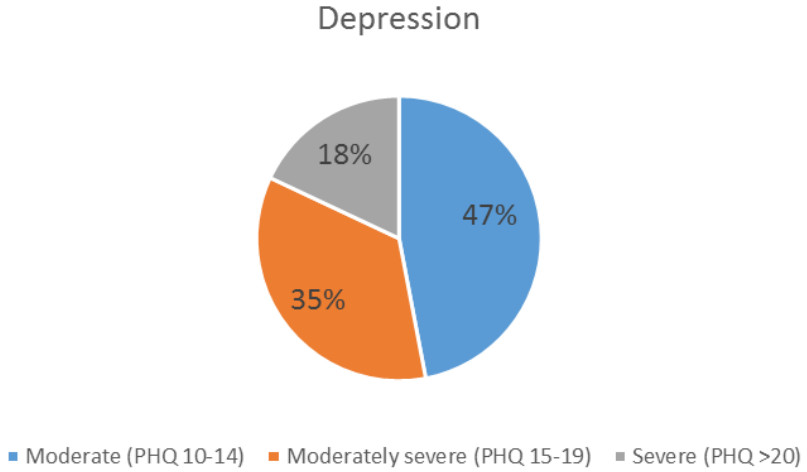
The impairment severity distribution among those people who underwent a clinical screen and were found to have a moderate or severe impairment is shown in Graph 5.

Unextrapolated, raw data can be found in table a8 in the Appendix for comparison.









Graph 5: Severity of clinical impairment

6.2 Comparison of people with and without disabilities from the survey data

Key Messages in this section:

- **We compared people with and without disabilities identified in the survey and found that people with disabilities were significantly more likely to be older, female, poorer, unmarried and less educated than the general population**
- **31% of households included at least one person with a disability**
- **Households with at least one person with a disability were larger average number of household members, poorer, had a higher average age and a higher dependency ratio than households without any members with disabilities**
- **Disability was not found to be associated with ethnic group or living in a rural versus urban location either at the individual or household level**

We compared the socio-demographic and economic characteristics of people with and without disabilities identified in the national survey (table 13). There was a strong association between age and disability, with disability being much more common in the older age groups (adjusted ORs (aOR) for 50+ years (adjusted odds ratios, aOR: 11.3, 95% CI 7.5 – 17.2) and women were 1.5 times (95%CI 1.3-1.7) more likely than men to have a disability. There was significant variation in disability status by region but no significant difference by urban versus rural location or ethnic group was observed after adjusting for confounders.

People with disabilities were significantly more likely to be in the lowest or middle quintiles than the highest (wealthiest), including being 1.5 times more likely to be in the poorest quintile (aOR 1.5, 1.2 – 2.0). Among adults aged 18+ years people with disabilities were much less likely to have been educated to secondary (aOR 0.5, 0.4-0.7) or university level (aOR 0.3, 0.2 – 0.5) compared to people without disabilities although there was no significant difference in literacy. Adults with disabilities were also slightly more likely to have never to have married/lived with a partner (aOR 1.3, 1.1 – 1.6).

Table 13: Characteristics of people with and without disabilities in the national survey

N (%)	People without disabilities (n=11,742) N (%)	People with disabilities (n=1,331) (N (%)	Age, Sex, Region, SES adjusted OR (95% CI)
Age group (years)			
2-4	1,038 (9%)	31 (2%)	Baseline
5-17	4,142 (35%)	258 (19%)	2.1 (1.4 – 3.2)*
18-49	5,017 (43%)	552 (42%)	3.6 (2.4 – 5.5)*
50+	1,545 (13%)	490 (37%)	11.3 (7.5 – 17.2)*
Sex			
Male	5,534 (47%)	499 (37%)	Baseline
Female	6,207 (53%)	832 (63%)	1.5 (1.3 – 1.7)*
Region			
Central	1,856 (16%)	345 (26%)	Baseline
North East	2,574 (22%)	166 (13%)	0.3 (0.2 - 04)*
North West	2,249 (19%)	394 (30%)	0.9 (0.7 – 1.2)
South East	2,685 (23%)	152 (11%)	0.3 (0.2 – 0.3)*
South West	2,378 (20%)	274 (21%)	0.6 (0.4 -0.7)*
Location			
Rural	7,312 (62%)	727 (55%)	Baseline
Urban	4,430 (38%)	604 (45%)	1.2 (0.9 – 1.4)
Ethnicity			
Mayan	5,359 (46%)	628 (47%)	Baseline
Latino/Mix	5,841 (50%)	652 (49%)	1.2 (1.0 – 1.4)
Other	136 (1%)	12 (1%)	1.5 (0.8 - 2.8)
Not specified	406 (3%)	39 (3%)	1.0 (0.6 – 1.5)
Socio-economic status			
1st (poorest)	2,587 (22%)	281 (21%)	1.5 (1.2 – 2.0)*
2nd	2,576 (22%)	279 (21%)	1.4 (1.1 – 1.7)*
3rd	2,329 (20%)	273 (21%)	1.4 (1.1 – 1.8)*
4th	2,217 (19%)	262 (20%)	1.2 (1.0 – 1.6)
5th (wealthiest)	2,033 (17%)	236 (18%)	Baseline
Highest education level			
None	1,330 (20%)	381 (37%)	Baseline
Primary	2,725 (42%)	453 (44%)	0.8 (0.7 – 1.0)
Secondary	2,146 (33%)	179 (17%)	0.5 (0.4 – 0.7)*
University	324 (5%)	21 (2%)	0.3 (0.2 – 0.5)*
Literacy			
Well	3,488 (53%)	472 (45%)	0.8 (0.6 – 1.0)
Little	1,602 (24%)	276 (26%)	1.0 (0.8 – 1.2)
Not at all	1,472 (22%)	294 (28%)	Baseline
Marital status			
Married/living together	4,386 (67%)	647 (62%)	Baseline
Divorced/separated	279 (4%)	66 (6%)	1.4 (1.0 – 1.8)
Widowed	281 (4%)	148 (14%)	1.4 (1.0 – 1.7)
Never married/lived with another	1,615 (25%)	180 (17%)	1.3 (1.1 – 1.6)*
*p<0.05			

Households with and without members with a disability

In total 3095 households were included in the survey, of which 972 (31%) included at least one person with a disability. Just under three quarters (n=709, 73%) of these households included only one person with a disability, 20% (n=193) of households included two people with disabilities and 7% of households included 3-5 people with disabilities.

We compared demographic and economic characteristics of households with and without disabilities. Average household size and the average age of household members was significantly greater among households with, compared to households without a member with a disability (p<0.001, Table 14). There was no significant difference in the SES index score between these two groups, however there were some differences in other economic indicators. The proportion of people working out of a) working aged household members and b) all household members working was significantly lower in households with members with a disability (p<0.001). Households which included a person with a disability also had a greater dependency ratio (p<0.001).

Table 14: Characteristics of households with and without a member with a disability

Characteristics	Households without members with a disability (N=2,123)	Households with members with a disability (N=972)	
	Mean (95% CI)	Mean (95% CI)	**P-value**[a]
% female	47.2% (46.2-48.2)	46.8% (45.3-48.3)	0.69
Average household size	4.8 (4.7-4.9)	5.4 (5.2-5.5)	<0.001
% working among age	52.8% (51.6 – 54.1)	48.8% (47.0 – 50.7)	<0.001
% of all household members working	37.9% (36.8 - 38.9)	34.6 (33.2 – 36.0)	<0.001
SES index score	0.03 (-0.08 – 0.14)	-0.07 (-0.22 – 0.09)	0.32
	Median (SD)	Median (SD)	**P-value**[b]
Average age (years)	25 (13.8)	28 (15.8)	<0.001
Number of dependents	1 (1.4)	2 (1.5)	<0.001
Number of independents	2 (1.7)	3 (1.9)	<0.001
Dependency ratio[c]	0.5 (0.7)	0.7 (0.8)	<0.001

Means (95%CI) or medians (SD) are presented depending on distribution of the data. P-value from [a]t-test or [b]Mann-Whitney test; [c] Dependency Ratio: ratio of dependents (<15 years and >65 years) to independents (15-64 years) living in the household; SES Socio-economic Status

In the adjusted logistic regression analysis (table 15), households with older average age were more likely to include a member with a disability. Households with disabilities were less common among the north east, and south east regions (p<0.001). There was no significant difference in household disability status by proportion of household members that were female, highest education level of any household member or ethnicity.

In terms of economic indicators, households with members with disabilities were more likely to be in the lowest socio-economic group (aOR 1.7, 1.3 – 1.8). Households with members with a disability were much more likely to have higher dependency ratio (ratio greater than 1.0 compared to less than 0.25: aOR 2.5, 1.9 – 3.2).

Table 15: Comparison of households with and without a member with a disability

	Households without members with a disability (N=2,123)	Households with members with a disability (N=972)	Region, average age, proportion female and SES adjusted OR
	N (%)	**N (%)**	**Adjusted OR (95% CI)**
Average age (years)			
<20	600 (28%)	172 (18%)	Baseline
20-39	1,168 (55%)	570 (59%)	1.8 (1.5 – 2.2)*
40+	355 (17%)	230 (24%)	2.7 (2.1 – 3.4)*
Proportion of household female[a]			
0-25%	315 (15%)	147 (15%)	Baseline
25-50%	641 (30%)	336 (35%)	1.2 (0.9 – 1.5)
51-75%	874 (41%)	343 (35%)	0.8 (0.6 – 1.0)
76-100%	293 (14%)	146 (15%)	1.0 (0.8 – 1.4)
Region			
Central	408 (19%)	246 (25%)	Baseline
North East	467 (22%)	136 (14%)	0.4 (0.3- 0.6)*
North West	313 (15%)	244 (25%)	1.2 (0.9 – 1.5)
South East	505 (24%)	128 (13%)	0.4 (0.3 – 0.5)*
South West	430 (20%)	218 (22%)	0.8 (0.6 – 1.0)
Ethnicity			
Mayan	858 (40%)	445 (46%)	Baseline
Latino/Mix	1,171 (55%)	483 (50%)	1.0 (0.8 – 1.2)
Other	25 (1%)	10 (1%)	1.3 (0.6 – 2.8)
Not specified	69 (3%)	34 (4%)	1.0 (0.7 – 1.6)
Socioeconomic status			
1st (poorest)	527 (25%)	247 (25%)	1.7 (1.3 – 2.2)*
2nd	531 (25%)	251 (26%)	1.5 (1.2 – 2.0)*
3rd	530 (25%)	236 (24%)	1.4 (1.1 – 1.8)*
4th	535 (25%)	238 (24%)	6.1 (1.0 – 1.7)
5th (wealthiest)			Baseline
Dependency ratio			
0-0.25	639 (30%)	223 (23%)	Baseline
0.26-0.50	520 (24%)	228 (23%)	1.6 (1.3 – 2.0)*
0.50-1.0	598 (28%)	322 (33%)	2.0 (1.6 – 2.5)*
>1.0	366 (17%)	199 (20%)	2.5 (1.9 – 3.2)*
Proportion working age working			
0-25%	517 (24%)	325 (33%)	1.6 (1.2 – 2.0)*
25-50%	880 (41%)	335 (34%)	1.3 (1.0 – 1.6)
51-75%	247 (12%)	117 (12%)	1.2 (0.9 – 1.6)
76-100%	479 (23%	195 (20%)	Baseline
Proportion of household working			
0-25%	555 (26%)	291 (30%)	3.1 (2.1 – 4.6)*
25-50%	662 (31%)	308 (32%)	2.2 (1.5 – 3.2)*
51-75%	528 (25%)	229 (24%)	1.8 (1.2 – 2.8)*
76-100%	378 (18%)	144 (15%)	Baseline

[a]Refers to the proportion of female household members amongst all household members; *significant (p<0.05)

6.3 Findings from the case control study

Study population

A total of 707 people with disabilities ('cases') and 467 people without disabilities ('controls') were included in the case-control study. The total number of controls is lower than the number of cases due to high prevalence of disability in older adults, limiting the availability of eligible controls in this age group. Cases were well matched with controls on sex, but cases were over-represented in the oldest age category (66+ cases: 24%, controls 12%, p<0.001) (Table 16). To account for imperfect matching all case/control comparative analyses were adjusted for age and sex.

Table 16: Age, sex and geographical distribution of cases and controls

	People with disabilities (n=707)		People without disabilities (n=465)		P-value (chi square)
	N	(%)	N	(%)	
Age Group					
5-14	95	13	79	17	<0.001
15-24	96	14	103	22	
25-54	266	38	182	39	
55-64	80	11	47	10	
65+	170	24	54	12	
Sex					
Male	253	36	163	35	0.8
Female	454	64	301	65	
Region					
Central	194	27	123	26	
North-East	66	9	50	11	0.003
North-West	233	33	110	24	
South-East	55	8	54	12	
South-West	159	22	128	28	

Socio-economic characteristics of people with and without disabilities

Key Findings from this section

- **Adults with disabilities were less likely to have ever attended school and were more likely to be illiterate compared to adults without disabilities.**
- **Children with disabilities were less likely to have their biological father living in the same home as them.**

We did not see any difference in the SES level of people with and without disabilities, however there were some differences in other economic indicators (table 17): people with disabilities were nearly two times more likely to have never attended school (OR 1.9, 1.1 – 3.0) or have completed primary only (OR 1.6, 1.1 – 2.4) compared to secondary school and were more likely to be illiterate (OR 1.9 1.3 – 2.8). People with disabilities were also more likely to have never married or lived with a partner (OR 1.7, 1.1 – 2.5) although no significant difference was observed for being widowed/divorced. Children with disabilities were less likely to have their biological father living in the same home as them compared to children without disabilities (OR 0.5, 0.3-1.0)

Table 17: Socio-economic characteristics of people with and without disabilities

	People with disabilities		People without disabilities		Age, Sex, Region, SES adjusted OR (95% CI)
	N	(%)	N	(%)	
SES					
1st Quartile (poorest)	155	22	116	25	0.9 (0.6 – 1.2)
2nd Quartile	198	28	120	26	1.1 (0.8 – 1.5)
3rd Quartile	182	26	118	25	1.0 (0.7 – 1.4)
4th Quartile (richest)	172	24	111	24	baseline
Highest Education[a] (adults only)					
No school	208	36	96	28	1.9 (1.1 – 3.0)*
Primary	268	47	155	45	1.6 (1.1 – 2.4)*
Secondary or higher	99	17	96	28	baseline
Literacy (adults only)					
Can read well	199	34	168	48	baseline
Can read a little	167	29	95	27	1.4 (0.9 – 2.0)
Cannot read at all	212	37	89	25	1.9 (1.3 – 2.8)*
Marital Status (adults only)					
Married/living together	354	61	234	67	baseline
Widowed/divorced	119	21	52	15	1.1 (0.8 – 1.7)
Never married/lived with a partner	103	18	64	18	1.7 (1.1 – 2.5)*
Biological Father lives at home (children only)					
Yes	83	64	86	76	0.5 (0.3 – 1.0)
[a]Data were missing 3 cases and 5 controls *p<0.05					

Children and education

Key Findings: Children and education

- **Overall, 83% of children without disabilities and 76% of children with disabilities were attending school**
- **In rural areas, children with disabilities were significantly less likely to be attending school (61%) compared to children without disabilities (82%). In urban areas, school attendance was over 80% for both children with and without disabilities.**
- **School attendance was significantly lower among girls with disabilities (69%) compared to girls without disabilities (84%). There was no significant difference in school attendance between boys with and without disabilities.**
- **No differences were observed in terms of repeated grades and school days missed in the last month**
- **Among children with disabilities only:**
  - **School attendance among children was much higher in urban compared to rural areas**
  - **School attendance was lowest for children with significant limitations in physical and cognitive functioning.**

School attendance among children with and without disabilities

Overall school attendance was slightly lower for children with disabilities (76%) compared to controls (83%) but this was not statistically significant (table 18). However, in rural areas, children with disabilities (62% attendance) were significantly less likely to be attending school compared to children without disabilities (82% attendance, aOR 0.4, 0.2-0.9). No such difference was evident in urban areas where school enrolment was at least 80% for both groups. We also found that school attendance was significantly lower among girls with disabilities (69%) compared to girls without disabilities (89%, aOR 0.3, 0.1-0.9). No such no difference was observed amongst boys with and without disabilities.

Table 18: School attendance stratified by age, sex and urban rural location

	Children with disabilities		Children without disabilities		Age, sex, location adjusted OR (95% CI)
	N	%	N	%	
All children	98	76	94	83	0.6 (0.3 – 1.2)
Age (years)					
5-8	32	91	34	85	0.7 (0.2-2.6)
9-12	28	68	20	74	0.2 (0.01-2.0)
13-17	40	74	41	79	0.8 (0.4-2.3)
Sex					
Male	47	82	40	77	1.2 (0.5-3.4)
Female	51	69	54	84	0.3 (0.1-0.9)*
Location					

Rural	42	61	53	82	0.4 (0.2-0.9)*
Urban	56	90	41	80	1.8 (0.5-6.5)

*significant (p<0.05)

Among those attending school, the majority of both cases (94%) and controls (90%) were reported to be in the same grade as other children their age and there were no significant differences in reported number of school days missed in the last year.

Table 19: Education and family dynamics among children with and without disabilities

	Children with disabilities N	(%)	Children without disabilities N	(%)	Age, Sex, Region, SES adjusted OR (95% CI)
Same grade as other children					
Yes	92	94	85	90	1.7 (0.6 – 5.4)
Days missed in last month					
None	53	54	56	60	Baseline
1-4	35	36	30	32	1.0 (0.5 – 2.0)
5+	10	10	8	9	1.4 (0.5 – 4.2)

Factors associated with school attendance among children with disabilities

We also explored whether there were differences in school attendance among the children with disabilities according to socio-demographic characteristics and type of functional limitation (See table a1 in Appendix). This showed that school attendance was higher among children with disabilities aged 9-12 years compared to those aged 5-8 years (aOR 3.8-1.0-14.2). Children with disabilities living in urban areas were much more likely to attend school compared to those in rural areas (aOR 7.4, 2.6-21.3). School attendance was lower among girls than boys, although this was not statistically significant. Children with significant limitations in physical (aOR 0.2, 0.02-1.0) or cognitive (aOR 0.3, 0.1-0.9) functioning were the least likely to be enrolled in school.

The number of children in some regions was small, limiting the ability to assess statistical association with region. However, the data suggest some variation in school attendance by region: attendance was highest in the Central region (94% of the 34 children) and was between 74-78% for the North East, North West and South West. In contrast, in the South East only 2 of the 9 children were attending school (22%).

Work and Employment (adults aged 18+ years)

Key findings: work and employment (adults)

- **Overall, adults with disabilities were significantly less likely to have worked in the previous week compared to controls.**
- **Adults with disabilities had less stable livelihood opportunities: they were more likely than adults without disabilities to report working only once in a while compared to throughout the year. No differences were observed in type of work or type of payment.**
- **There were also differences in reported reasons for not working: others (household members/ employers) not allowing and poor health were more commonly reported by people with disabilities.**
- **Adults with disabilities were more likely to report having a retirement pension and family allowance compared to people without disabilities. Access to non-state support (social security benefits, cash for work schemes and remittances) was low for people with and without disabilities (<5%).**
- **Among adults with disabilities, the likelihood of work was significantly lower among:**
    - **Older adults (>50 years)**
    - **Females compared to males**
    - **People who had never married/lived with a partner**
    - **People with significant physical functional limitations**

Working status among adults with and without disabilities

Adults with disabilities were significantly less likely to have worked in the previous week compared to controls even after multivariate adjustment (OR 0.6, 0.4-0.8, table 20). To explore this further, we compared working status between people with and without disabilities separately by age group, sex, rural/urban location and region (Table 21). By age group, the trend of people with disabilities being less likely to work was significant among adults aged 35-49 (aOR 0.6, 0.3-1.0) and 65+ years (aOR 0.2, 0.1-0.4). Males with disabilities were much less likely than males without disabilities to work (aOR 0.2, 0.1-0.4), whereas among females there was no significant difference. In urban areas people with disabilities were significantly less likely to be working (aOR 0.4, 0.2-0.7), but this difference was not significant in rural areas. In terms of region, people with disabilities were less likely to work in Central, North East and South West regions.

Among people who reported having worked in the past week, cases were significantly more likely than controls to report working “only once in a while” compared to throughout the year (aOR 1.8, 1.1-2.9). There were no case control differences in type of work or payment type.

Among those not working there was some differences in reported reasons for this. People with disabilities were more likely to report poor health (aOR 3.3, 1.6-6.7) and much more likely to report that either household members or employers would not allow them to work (OR 11.0, 3.0 – 40.0).

Table 20: Working in the past week among adults with and without disabilities aged 18+ years (full sample and stratified by age, sex, location and region)

	Adults with disabilities (n=578) N	%	Adults without disabilities (n=352) N	%	Age, sex, SES adjusted OR (95% CI)
All adults	194	34	166	47	0.6 (0.4-0.8)
Age (years)					
18-34	68	47	72	48	0.9 (0.6-1.5)
35-49	62	44	41	51	0.6 (0.3-1.0)*
50-64	42	36	31	47	0.6 (0.3-1.3)
65+	22	13	22	41	0.2 (0.1-0.4)*
Sex					
Male	85	44	85	77	0.2 (0.1-0.4)*
Female	109	28	80	33	0.9 (0.6-1.2)
Location					
Rural	103	33	79	40	0.8 (0.5-1.2)
Urban	91	34	87	56	0.4 (0.2-0.7)*
Region					
Central	64	40	49	59	0.5 (0.3-0.9)*
North East	13	23	18	45	0.3 (0.1-0.9)*
North West	71	39	36	49	0.9 (0.5-1.8)
South East	8	17	12	27	0.7 (0.2-2.2)
South West	38	29	51	47	0.5 (0.3-0.8)*

*significant ($p<0.05$)

Table 21: Type of work among working adults with and without disabilities

	Adults with disabilities (N= 578)		Adults without disabilities (N=353)		Age, Sex, Region, SES adjusted OR (95% CI)
	N	(%)	N	(%)	
Type of work					
Work for own business	116	44	82	40	Baseline
Work for other's business	101	38	92	45	0.9 (0.6 – 1.4)
Work on own farm	18	7	18	9	0.9 (0.4 – 1.9)
Other	30	11	14	7	1.8 (0.9 – 3.8)
Work Security					
Works throughout year	145	55	137	67	Baseline
Works seasonally/part of year	39	15	30	15	1.2 (0.7 – 2.1)
Works once in a while	79	30	39	19	1.8 (1.1 – 2.9)*
Payment					
Cash only	207	79	169	82	Baseline
Other	14	5	11	5	1.2 (0.5 – 2.7)
Not paid	42	16	26	13	1.0 (0.6 – 1.8)
Reasons not working[a]					
Childcare/household duties	107	34	87	58	Baseline
Age related	56	18	19	13	0.8 (0.4 – 1.9)
Poor Health	86	27	15	10	3.3 (1.6 – 6.7)*
Others will not allow	43	14	3	2	11.0 (3.0 – 40.0)*
No opportunities in area	13	4	16	11	0.7 (0.3 – 1.6)
Other	10	3	9	6	1.1 (0.3 – 3.2)

*significant ($p<0.05$)

In terms of access to formal support, among adults aged 60+ years, people with disabilities were more likely to report having a retirement pension (OR 2.4, 1.0 – 5.6) and family allowance (1.6, 1.0-2.6) compared to people without disabilities (Table 22). Access to non-state support (social security benefits, cash for work schemes and remittances) was low for people with and without disabilities (<5%).

Table 22:Access to formal support among people with and without disabilities aged 60+ years

	Adults with disabilities (n=210)		Adults without disabilities (n=78)		Age, Sex, Region, SES adjusted OR (95% CI)
	N	(%)	N	(%)	
State Support					
Retirement Pension[a]	41	20	8	10	2.4 (1.0 – 5.6)
Disability Pension	8	1	0	-	-
Family Allowance	81	14	27	8	1.6 (1.0 – 2.6)
Non-state support					
Social Security Benefits	24	4	19	5	0.8 (0.3 – 1.5)
Cash for Work Schemes	18	3	15	4	0.5 (0.1- 3.2)
Remittances	24	4	17	5	0.5 (0.1 – 3.2)

Factors associated with work status among adults with disabilities

Among adults with disabilities the likelihood of working in the past week decreased with age and was significantly lower among people aged 50-64 years (aOR 0.6, 0.4-1.00) and those aged 65 years and older (aOR 0.1, 0.1-0.2) compared to younger adults (18-34 years) (See table a2 in Appendix). Females with disabilities were substantially less likely to have worked in the past week compared to males (aOR 0.3, 0.2-0.5). There was some association with marital status; people who had never married or lived with a partner being less likely to be working compared to people who were married/co-habiting (aOR 0.6, 0.3-1.0). Being educated to secondary or higher levels was predictive of working (aOR 1.9, 1.1-3.5). In terms of type of functional limitation, people with significant physical limitations were less likely to be working compared to people without physical limitations. No significant difference in working status was seen for other functional domains. Ethnicity, region and urban/rural location were not significantly associated with having worked in the past week.

Water, Sanitation and Hygiene (WASH)

Key Findings: Water Sanitation and Hygiene

- **Access to improved sanitation and water supplies was high for both households with and without a person with a disability**
- **Persons with disabilities were slightly less likely to report being able to use the same facility as other household members and to be able to use toilet facilities without faecal contact.**

Water and sanitation among people with and without disabilities

According to the WHO/UNICEF Joint Monitoring Programme, water and sanitation facilities are considered improved if the water source is protected from outside contamination (particularly from

faecal matter), and the sanitation facility separates human exreta from human contact. (see wssinfo.org)

As shown in Table 23, the majority of both people with and without disabilities had improved sanitation (cases 89%, controls 85%) and did not share latrine facilities with other households (92%). People with disabilities were slightly less likely to have unimproved facilities compared to people without (0.5 95% CI 0.3 – 0.8). Nearly all people with disabilities (98%) and people without (97%) had improved water facilities and for 87% of case and 85% controls' water source is in the dwelling.

There were some differences in water and sanitation access. People with disabilities were slightly less likely to report being able to use the same facility as other household members (0.2 (0.1 – 0.4), although the proportion who could access the same facilities was still high (94%, compared to people without disabilities 99%). People with disabilities were also slightly less likely to report that they could use the toilet facilities without faecal contact (OR 0.8 95%CI 0.6-1.0) and without assistance from others (OR 0.6 95%CI 0.4 – 0.8). There were no case control differences with being able to access drinking water as needed in the households (87% both).

Table 23: WASH among people with and without disabilities (all ages)

	People with disabilities (n=707) N (%)		People without disabilities (n=465) N (%)		Age, Sex, Region, SES adjusted OR (95% CI)
Sanitation Facility					
Improved	630	89	391	84	Baseline
Unimproved	56	8	58	13	0.5 (0.3 – 0.8)*
No Facility	21	3	16	3	0.9 (0.4 – 1.9)
Use same facility as other household members					
Yes	666	94	460	99	0.2 (0.1 – 0.4)*
Use facility without faecal contact					
Yes	500	71	352	76	0.8 (0.6 – 1.0)
Use facility without assistance from others					
Yes	528	75	389	84	0.6 (0.4 – 0.8)*
Water Facility					
Improved	695	98	450	97	Baseline
Unimproved	12	2	15	3	0.6 (0.3 – 1.4)
Collect water for drinking					
Yes	526	74	382	82	0.7 (0.5 – 1.0)

*p<0.05

Factors associated with quality of toilet access among people with disabilities

We explored the relationship between indicators of quality of toilet access (reporting usually coming into contact with faeces when using the toilet and needing assistance with using the toilet) and socio-demographic characteristics and type of functional limitations among people with disabilities and found few significant associations (see Tables a3 and a4 in appendix. The exceptions were that people of working age compared to children (5-17 years) were less likely to report usually coming into contact

with faeces (aOR 0.6, 0.4-1.0) and people from the South East region were more likely (vs central aOR2.2, 1.2-4.1). Compared to those who were married/co-habiting, people who had never been married/lived with a partner were more likely to report contact with faeces (aOR 1.8, 1.1-3.0) and needing assistance with using the toilet (aOR 2.3, 1.4-3.9) and being widowed/divorced was also associated with needing assistance with toilet use (aOR 1.7, 1.0-2.8).

Participation and environment

Key Findings: Participation and Environment

- **Overall, people with disabilities had higher participation restrictions compared to people without disabilities in the areas of independent or supported self-care, domestic life, interpersonal behaviours, major life areas (school and work) and community/civic life areas.**
- **Among people with disabilities:**
  - **Significantly greater participation restrictions were found among older adults, males, people living in the North East and South East regions, adults who were widowed/divorced or never married/lived with a partner and adults with no formal education.**
  - **Participation scores were lowest for people with significant limitations in physical, communication and multiple domains**
- **In general, people with disabilities reported greater environmental barriers across different environmental domains (such as transport, the natural environment and availability and accessibility of services) and across each age group.**

Participation among people with and without disabilities

Participants were asked about their ability to perform a range of activities in their current environment (including with the assistance of any person or assistive device they currently used) in the areas of independent or supported self-care, domestic life, interpersonal behaviours, major life areas (school and work) and community/civic life areas.

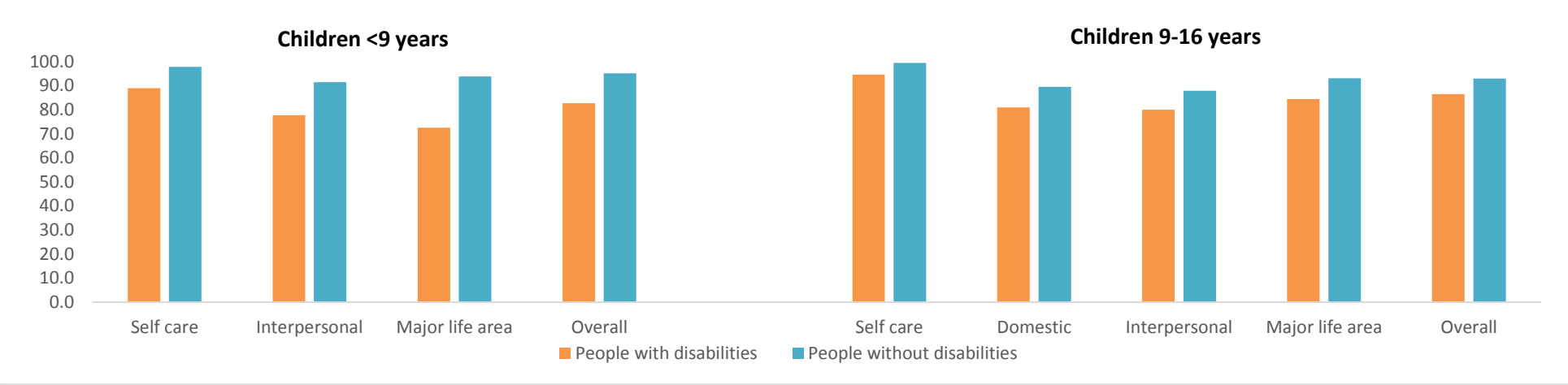
As shown in Graph 6, mean participation scores were consistently significantly lower (indicating greater participation restrictions) for people with compared to without disabilities across the different age groups. The only exception was for self-care and major life areas (schooling) among children where the difference was not significant.

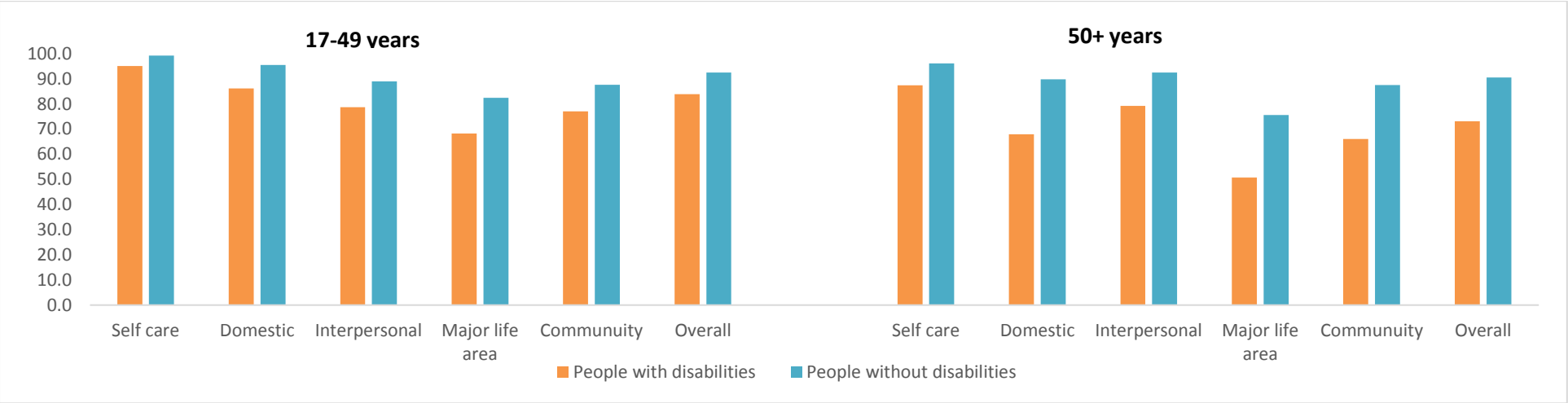
Factors associated with participation among people with disabilities

Among people with disabilities, significantly greater participation restrictions were found among older adults ($p<0.001$), males ($p<0.001$), people who were widowed/divorced ($p=0.03$) or never married/lived with a partner ($p<0.001$) and people with no formal education (($p<0.001$) (Appendix table a5). Participation scores were significantly lower among people with disabilities in the North East

($p<0.001$) and South East ($p<0.001$) compared to the central region. In terms of functional limitations, the lowest participation scores were found among people with significant limitations in physical ($p<0.001$), communication ($p<0.001$) and multiple domains ($p<0.001$). No association was seen with ethnicity, SES or education.

Graph 6: Participation scores among people with and without disabilities





*Lower scores indicate greater participation restrictions; Participation scores for people with disabilities were significantly poorer in all domains except self-care among <9 years and major life areas for 9-16 years

Environment among people with and without disabilities

Table 24 shows the means scores for the 12 environment questions which asked about the frequency at which elements of the built and natural environment created barriers. In general people with disabilities had significantly lower scores (reflecting worse environmental barriers) compared to controls. These exceptions were in the following domains: availability of health care services, the attitude of other people at home (50+ years only), the attitude of other people at work (adults only) and governmental programmes (adults only) which were not significantly different for people with and without disabilities.

Table 24: Frequency of built and natural environment created barriers among cases and controls

	5 to 17			**18 to 49**			**50+**		
Environmental Domains	Cases (mean) n=129	Controls (mean) n=113	p	Cases (mean) n=288	Controls (mean) n=234	p	Cases (mean) n=290	Controls (mean) n=118	p
Transport	4.3	4.5	0.3	3.8	4.3	<0.001	3.9	4.3	0.01
Natural environment	4.4	4.7	0.02	4.2	4.6	0.01	3.8	4.5	<0.001
Surroundings	4.3	4.7	0.01	4.2	4.6	<0.001	4.1	4.5	0.01
Format of information	4.4	4.7	0.01	4.2	4.4	0.04	4.1	4.4	0.02
Availability of health care services	4.3	5.0	0.3	4.0	4.3	<0.001	3.9	4.1	0.1
Availability of assistance at home	4.4	4.7	0.02	4.2	4.4	0.05	4.2	4.5	0.03
Availability of assistance at school/work	4.5	4.8	0.01	4.4	4.6	0.01	4.4	4.8	0.01
Other people's attitudes (at home)	4.3	4.7	0.04	4.3	4.5	0.02	4.6	4.7	0.3
Other people's attitudes (at school/work)	4.5	4.8	0.04	4.6	4.7	0.1	4.8	4.8	1.0
Prejudice and discrimination	4.5	4.8	<0.001	4.4	4.6	<0.001	4.5	4.6	0.3
Policies and rules (Organisations)	1.5	1.7	0.2	1.4	1.7	<0.001	1.3	1.5	0.03
Government programmes and policies	4.8	5.0	0.01	4.8	4.8	0.4	4.8	4.8	0.8

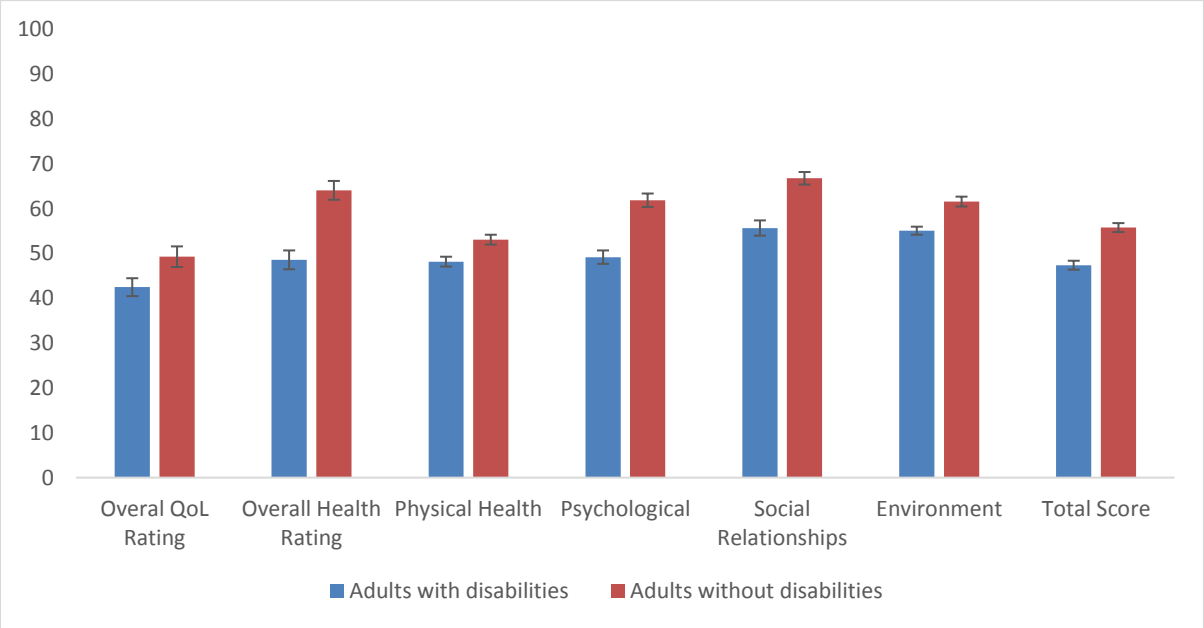
Quality of life among adults

Key Findings: Quality of life (QoL)

- **QoL scores were consistently poorer for people with disabilities overall and in each of four the sub-scales (physical health, psychological, social relationships and environment).**
- **Among people with disabilities:**
  - **Being poorer, living in rural areas and living in the North East and South East regions was associated with having poorer QoL.**
  - **People reporting significant limitations with physical, cognitive, anxiety/depression, communication, and multiple domains reported poorer QoL (p<0.001) compared to people without significant limitations in the corresponding domains/group**

Quality of life among adults with and without disabilities

Quality of life scores were significantly poorer among people with disabilities compared to controls (p<0.001, Graph 7). This difference was observed for overall scores and within the four sub-scales. This relationship remained consistent if we compared QoL of people with and without disabilities separately by age group, sex, location and region.



Graph 7: Quality of life among adults with and without disabilities

NB: Lower score denotes poorer QoL; scores were significantly lower for adults with disabilities in each domain)

Factors associated with QoL among adults with disabilities

There was a significant association between QoL and SES: QoL was lowest among adults in the poorest SES group and improved with increasing SES (p<0.001) (Table Appendix a7). QoL scores were significantly higher among adults living in urban compared to rural areas (p=0.05) and among adults who had completed secondary or higher education compared to those with no formal schooling (p<0.001). There was also some regional variation with significantly lower QoL scores found in the North East (p=0.004) and South East (p=0.001) regions. No significant association was seen between QoL and sex, age, ethnicity and marital status.

In terms of functional domain, people reporting significant limitations with physical, cognitive, anxiety/depression, communication, and multiple domains reported poorer QoL (p<0.001) compared to people without significant limitations in the corresponding domains/group. No such difference was observed for the vision or hearing domain.

Health

Key Findings: Health

- **People with disabilities were more likely to have reported a serious health problem in the past 12 months**
- **There were no significant differences in health seeking behaviour between people with and without disabilities (whether sought care and place of care)**
- **In terms of experience of health care, people with disabilities were more likely to report being disrespected and more likely to find it difficult to understand information given to them at health centres.**
- **Among people with disabilities, reporting a serious health problem was more common among adults and people with limitations in physical, anxiety/depression and multiple domains.**
- **Women of reproductive age (15-49 years) with disabilities were less likely to have sought antenatal care in their last pregnancy (with the past 5 years). However, they were more likely than women without disabilities to have delivered their baby in a health centre or hospital (rather than at home) and have the birth assisted by a doctor.**
- **No major differences were observed between numbers of children or vaccination status of their children between women with and without disabilities.**
- **Vaccination coverage was high for both children with and without disabilities**

Health access among people with and without a disability

Cases were nearly three times more likely to have reported a serious health problem in the past 12 months (aOR 2.8, 2.2-3.7), table 25. A similar proportion of cases (76%) and controls (72%) reported seeing advice or treatment for their most recent serious health problem. However, in terms of experience of health care services, cases were more likely to report being disrespected (aOR 1.9, 1.0-3.7) and more likely to report finding it difficult to understand information given (aOR 1.6, 1.1-1.4).

Table 25: Health care seeking and experience among cases and controls

	People with disabilities		People without disabilities		Age, Sex, Region, SES adjusted OR (95% CI)
	N	(%)	N	(%)	
Serious health problem past 12 months	333	47%	105	23%	2.8 (2.2-3.7)*
Sought advice/treatment	254	76%	78	72%	1.2 (0.7-2.1)
Where sought advice/treatment					
Government Health Centre	52	20%	23	28%	Baseline
Community Health Worker/ Health Post	10	4%	5	6%	1.1 (0.3-4.1)
Government/IGSS Hospital	93	36%	18	23%	1.9 (0.9-4.2)
Pharmacy	24	9%	4	5%	2.2 (0.6-7.5)
Private Clinic /Hospital	63	25%	27	35%	0.8 (0.4-1.6)
Traditional Healer/home remedy	12	5%	1	1%	-
Experience last time received health care					
How did you feel?					
Completely/mostly respected	435	81%	257	85%	
Neither respected nor disrespected	56	10%	31	10%	1.1 (0.7-1.7)
Completely/mostly disrespected	47	9%	13	4%	1.9 (1.0-3.7)*
Ease of understanding information					
Easy	308	57%	196	65%	
Neither easy nor difficult	109	20%	62	21%	1.0 (0.7-1.4)
Difficult	121	22%	42	14%	1.6 (1.1-1.4)*
Ease of being understood					
Easy	323	62%	193	64%	baseline
Neither easy nor difficult	108	20%	64	21%	0.9 (0.6-1.3)
Difficult	106	20%	43	14%	1.3 (0.8-1.9)

*excluding those who have never previously sought health care, $p<0.05$

Adult participants were asked about their awareness of and health seeking behaviour with regards to diabetes and hypertension (table 26). There were no significant differences between people with and without disability with regards to diabetes awareness, testing and type of treatment. With regards to blood pressure, 55% of people with, and 60% of people without disabilities, reported having had this checked and a higher proportion of cases reported having been told they have high blood pressure (OR 1.9, 1.4-2.8). However, no differences were observed in treatment received.

Table 26: Diabetes and high blood pressure among adults with and without disabilities

	People with disabilities N	%	People without disabilities N	%	Age, Sex, Region, SES adjusted OR (95% CI)
Diabetes					
Heard of diabetes	377	65%	239	68%	1.0 (0.7-1.3)
Had diabetes check	152	26%	83	24%	1.0 (0.7-1.4)
Told have diabetes	63	11%	26	7%	1.3 (0.7-2.1)
Receiving treatment for diabetes[a]					
Insulin	48	76%	15	58%	Baseline
Diet advice	10	16%	8	31%	0.4 (0.1-1.4)
None	5	8%	3	12%	0.7 (0.1-4.2)
Taking herbal/traditional remedy[a]	25	40%	11	42%	0.9 (0.3-2.5)
Blood Pressure					
Ever measured	344	60%	195	55%	1.2 (0.8-1.6)
Told have high blood pressure	160	28%	54	15%	1.9 (1.4-2.8)*
Receiving treatment [b]					
Medication	32	20%	14	26%	Baseline
Advice	58	36%	18	33%	1.1 (0.4-2.7)
None	70	44%	22	41%	1.2 (0.5-2.8)
Taking herbal/traditional remedy[b]	41	25%	16	30%	0.7 (0.3-1.4)

[a] people told by health professional that they have diabetes [b] Among people told they by health professional have high blood pressure, *p<0.05

Factors associated with reporting health problems and seeking health care among people with disabilities

Reporting a serious health problem in past 12 months was significantly more common among adults 18-49 (aOR 1.9, 1.2-2.9) and aged 50+ (aOR 3.3-2.1-5.1) compared to children. Reporting health problems was most common among people with significant limitations in physical 1.7 (1.2-2.5), anxiety/depression (aOR1.8, 1.3-2.5) and multiple domains (aOR 1.9, 1.3-2.7). No other socio-demographic characteristics were significantly associated with reporting a health problem among people with disabilities. There were few significant associations between socio-demographic/functional characteristics and seeking health care for the most recent serious health problem. The exceptions were that working age adults were less likely to have sought health care compared to children (aOR 0.3, 0.1-1.0)and people with multiple significant functional limitations were more likely to have sought care compare to those with reporting limitations in only one of the domains (aOR 1.5 , 1.8-2.7).

Women: Reproductive health

There were no significant differences between women (of reproductive age: 15-49 years) with and without disabilities in their mean number of pregnancies, children of previous pregnancies that did not reach full term (table 27).

Table 27: Mean number of pregnancies among women of reproductive age (15-49 years) with and without disabilities

	People with disabilities Mean (95%CI)	People without disabilities Mean (95%CI)	Adjusted P-value
Children ever born	2.5 (2.1-2.8)	2.3 (2.0-2.7)	0.43
Children living	2.1 (1.9-2.4)	2.1 (1.8-2.4)	0.37
Births ending before term	0.3 (0.2-0.4)	0.2 (0.1-0.3)	0.98

In terms of antenatal care for women who'd had children in the past 5 years, women with disabilities were less likely to have sought antenatal care during their pregnancy compared to controls (aOR 0.4, 0.1-1.0, Table 28. However, women with disabilities were much more likely than controls to have given birth at a health centre/hospital rather than home delivery (aOR 4.0, 1.4-11.6) and were more likely to have their birth assisted by a doctor (aOR 2.1, 0.9-5.0).

Table 28: Reproductive health: Questions asked most recent pregnancy in past 5 years

	People with disabilities (n=65)		People without disabilities (n=74)		Age, Sex, Region, SES adjusted OR (95% CI)
	N	(%)	N	(%)	
Antenatal care sought	50	77%	65	87%	0.4 (0.1-1.0)*
Place of delivery[a]					
Home	8	12%	23	31%	1.0
Health centre/hospital	57	87%	51	69%	4.0 (1.4-11.6)*
Who assisted delivery					
No-one/untrained TBA[b]	2	3%	3	4%	
TBA[b]	5	8%	16	23%	
Nurse[b]	8	13%	9	12%	Baseline
Doctor	75	81%	42	60%	2.1 (0.9-5.0)

[a]Cell numbers too small to compare between health care providers; [b] categories combined due to small cell numbers, *p<0.05

We asked about vaccination coverage for case/control adult caregivers of children aged <10 years and also for case/control children aged 5-9 years. Vaccination coverage was generally high and no differences were seen between cases and control vaccination status in either of those groups. In both groups just over two-thirds had a vaccination card and, among those with a card, coverage for BCG, Polio, MMR and DPT were over 80%.

Disability and rehabilitative services (People with disabilities only)

Key Findings: Disability and rehabilitation services (among people with disabilities only)

- **Illness (30%), aging (18%) and trauma (15%) were the most commonly reported causes of disability**
- **Awareness and perceived need of rehabilitation services amongst people with disabilities was relatively low (table 5)**
- **Overall reported use of assistive devices was low. Perceived unmet need was highest for vision aids (glasses and magnifying glass) and hearing aids.**

This section includes data on people with disabilities only. Table 29 shows the perceived main cause of their functional limitation. Illness was given as the most common cause (30%) followed by ageing (18%). The proportion due to trauma was reported to be 15% and war was not considered a common cause (1%). 6% of people with disabilities described their circumstances (including living in extreme poverty, and lack of employment opportunities) as the cause of their disability. In terms of age of onset, 12% reported their functional limitation was present at birth, adult onset was reported for 27% (18-49 years) and 40% (50+ years).

Table 29: Perceived cause and age of onset of functional limitation

	Cases (n=707) N	(%)
Main cause of functional limitation		
From birth	85	12%
Trauma	107	15%
Violence	46	7%
Illness	212	30%
Ageing	126	18%
War	9	1%
Related to Circumstances	39	6%
Other	14	2%
Unknown	69	10%
Age of onset of functional limitation		
From birth	73	12%
Child 0-4 years	31	4%
Child 5 – 17years	122	17%
Adult 18 – 49 years	194	27%
Older age (50 +)	278	40%

Table 30 shows awareness, perceived need and access of rehabilitative services among people with disabilities. Overall, both awareness (6.5- 27%) and perceived need (1.0-12.4%) for the different services/ information sources was relatively low. Awareness was particularly low for Community

Based Rehabilitation (6.5%) and legal advice services (9.5%) and highest for medical rehabilitation (25%) and health information (27%). Few people reported having accessed the different rehabilitative services (0.4-9.8%). This was lowest for CBR (0.4%) and highest for health information (12.4%). Only 4% of cases reported having ever received a specialist health services and 3.4% medical rehabilitation. Among people who reported needing the service, the proportion receiving it varied from 43% for CBR through to 70% for specialist health services. This indicates that even among people who are aware of and feel they need services, there are access gaps even for health services.

Table 30: Awareness and access to rehabilitation services among cases

	Have heard of services		Have needed services		Have Received Services		
	n	%	n	%	n	%[a]	%[b]
Medical Rehabilitation	176	25.0	39	5.5	24	3.4	62%
CBR	46	6.5	7	1.0	3	0.4	43%
Assistive Device Services	118	16.8	27	3.8	19	2.7	70%
Specialist Educational Services	111	15.8	15	2.1	8	1.1	53%
Vocational Training	70	10.0	9	1.3	6	0.9	67%
Counselling	113	16.1	32	4.6	22	3.1	69%
Welfare Services	122	17.4	28	4.0	15	2.1	54%
Health Information	190	27.0	87	12.4	69	9.8	79%
Traditional or Faith Healers	91	13.0	47	6.7	45	6.4	96%
Legal Advice	67	9.5	16	2.3	10	1.4	63%
Specialist Health Services	135	19.2	40	5.7	28	4.0	70%

CBR=Community Based Rehabilitation *Data missing for 5 cases; [a] % of all cases who have received service; [b] proportion of cases who received the service out of those who reported they needed it.

Persons with disabilities were also asked about their access to and awareness of assistive devices (Table 31). Overall, use of assistive devices was relatively low: glasses were reported to be used by 11.5% and walking stick by 5%, but use of the other assistive devices was less than 3%. Hearing aids were used only by 0.4%. Perceived unmet need was highest for vision aids (glasses (40%) and magnifying glass (18%) and hearing aids (12%).

Table 31: Awareness and access to assistive devices among cases

	Use device		Need but don't use device		Don't need device		Don't know what device is	
	n	%	n	%	n	%	n	%
Glasses	81	11.5	280	39.9	328	46.7	12	2
Magnifying Glass	16	2.3	129	18.4	319	45.4	237	33.8
Braille	1	0.1	9	1.3	239	34	452	64
White Cane	19	3	39	6	493	70	150	21
Hearing Aid	3	0.4	86	12	444	63	168	24
Wheelchair	23	3	39	6	577	82	62	9
Crutches	9	1	20	3	616	88	56	8
Walking Stick	37	5	40	6	523	75	101	14
Guide (another person)	11	2	19	3	547	78	124	18
Standing Frame	8	1	24	3	563	80	106	15
Prosthesis	6	1	7	1	502	72	186	27
*missing data for 5 cases								

6.4 Key Findings from the qualitative Component

This is an executive summary of the report ***Disability and Poverty in Rural Guatemala: Conceptual, Cultural and Social Intersections*** *by Shaun Grech, 2016. The full report is available at* http://disabilitycentre.lshtm.ac.uk.

Aims: The qualitative component of this study responds to the fact that qualitative research, in particular that listening to, prioritising and articulating the voices and perceptions of poor rural disabled people in Guatemala, remains scarce.

Objectives: To explore cultural, ideological, and social interpretations and responses to disability; provide insight into the disability and poverty relationship; and examine social, political, and economic dimensions operating within this relationship**.**

Methods: 27 in-depth interviews were conducted with disabled people and their family members in 4 rural areas (indigenous and non-indigenous) and thematic analysis was employed in the bid to find common themes and patterns in the data.

Key Findings:

Findings highlight a scenario of deep conceptual complexity, marking out disability as a notion and experience that that is fluid, heterogeneous and dynamic.

"..look around you, there is no work, the houses have water and animals coming in, and we have no money and sometimes no food, our children go hungry, hospitals treat us like dirt… and then comes this cursed illness, you have to pay money for doctors and you can't and then you can't buy food, what can I tell you? Look around you, how do you expect someone like me to survive here?" (Manuel)

This is accentuated by complex and heterogeneous traditional folk beliefs co-existing with a hegemonic Christian narrative. Overall, these influence how disabled people, families and communities understand and engage with disability over space and time.

The report maps out diverse social responses and attitudes that are not always negative, that operate along a spectrum, are dynamic, and importantly do not suggest systematic stigmatisation of disabled people. In the absence of safety nets and assets, families and poor communities for better or for worse are the only source of survival for disabled people. Findings continuously point to the predominance of shared poverty in rural communities as the point of focus and how disability is constructed, responded to and lived.

Deprivation, no access to safety nets, constrained livelihoods, infrastructural barriers, profound isolation and low assets among others are common realities that entrap all the poor. However, they also pitch poor people in competition with each other in contexts best described as 'survival of the fittest'. Findings suggest how within these spaces of deprivation, barriers tighten for disabled people and their families, in particular those related to livelihoods and health care, costs are accentuated for families that cannot cope with them. For indigenous families, these barriers bind with those related

to profound racism and xenophobia as well as remoteness, making the experience of disability and survival much harsher within these spaces.

Whole families are in turn cast into the most extreme and chronic poverty positioning these as the poorest of the poor- 'disabled families'. Findings highlight how this situation is created and perpetuated by deep structural inequalities and a policy and service landscape marked by disinterest in situation and plight of the poor, a landscape marked by profound gaps and barriers. Within these spaces, rights and international declarations, including the United Nations Convention on the Rights of Persons with Disabilities (CRPD) are often limited.

Recommendations for research, policy and practice:

- The need for more contextualised longitudinal research sensitive to cultural, personal and contextual diversity and heterogeneity and that looks at disability through a family perspective
- The need to adopt a twin-track and multi-sectoral approach to disability
- A call for policies and programmes that are knowledgeable of and responsive to the needs of the poor at large. This includes the requirement for universal social protection
- Support for and strengthening of families as opposed to focusing exclusively on the disabled person in isolation
- Strengthening of communities and building on strengths
- Alertness to and addressing of governance issues
- Creation of effective alliances between rural and urban organisations and other stakeholders

7. Discussion

Prevalence of disability

The estimated all-age prevalence of disability in Guatemala was 10.2%. This estimate refers to any reported functional limitation using the Washington Group Questions, at the level of "a lot of difficulty" or "cannot do"; as well as any reported functional limitation at the level of "some" difficulty in conjunction with a moderate or worse clinical impairment in the same domain.

The prevalence rose sharply with age from 5% of children 2 to 17, to 12% of adults 18-49 and 26% of adults aged 50 and above, which corresponds with other surveys of disability[1]. The prevalence estimates are higher than the 2005 Guatemala National Disability Survey, but comparable to other surveys in the region that have used a similar methodology[14]. For example, the Costa Rica 2011 Census, and Paraguay 2012 Census, both of which used the Washington Group Short Set of Questions (a shorter version than the Washington Group Questions used in this study, and without clinical screens), reported an all-age prevalence of 10.5% and 10.7% respectively. These findings underline the importance of using comparable methodologies for the determination of disability prevalence in population-based surveys across countries and over time.

The most common functional domains in which adults reported limitations in the survey were anxiety/depression (9.3%), mobility limitations (8%) and vision and hearing (both 4%). The most common domains in which children experienced significant limitations were in anxiety/depression (3%), maintaining relationships (1%) and mobility (1%). These findings are similar to the 2015 Global Burden of Disease (GBD) estimates for Guatemala, which rank low back and neck pain and depressive disorders in the top five health problems causing disability in the country[15].

The high prevalence of anxiety/depression is in stark contrast to the current 1.4% of public health spending, and 4% of medical degree course content, that is allocated to mental health in Guatemala[16]. Given the considerable stigma related to mental health, and the fact that it is a predominantly hidden disability, investment in support for people experiencing difficulties related to their mental health is urgently needed. In adults, almost twice as many women as men reported anxiety/depression (11.8% versus 5.9%). This finding has been seen in a number of other settings, highlighting the unmet mental health gap particularly for women as an area of great need[17 18].

Prevalence estimates varied by region, and were highest in the Central (all age disability prevalence of 16%) and North West (15%) regions, and lowest in the South East (5%) and North East (6%). This trend remained when stratified by age group and by sex (table 6). Reasons for the regional differences in prevalence are unclear and may reflect cultural differences in interpretation of the tools, as seen in other self-reported outcome tool validation studies[19]. For example, no differences were observed between regions in reporting "some difficulty" across domains (table 10), but higher proportions reported "a lot" or "cannot do" in the Central and North West regions than the North East and North West.

Another reason may be related to the Guatemalan Civil War (1960 – 1996). The higher prevalence of anxiety/depression and mobility limitations in the Central and North West regions correspond with several areas of prevalent military operations during the war – such as Quiché and Huehuetenango,

in the North West, and in the capital, Guatemala City (Central Region)[20]. Whilst an estimated 200,000 civilians were killed and 500,000 displaced by the Civil War, few figures are available on the impact of the war on both the physical and mental health of survivors[21].

Photo 6: Data Collection

One study by Rivera et al. (2008) estimated that of 1,841 individuals recorded as having a disability as a result of the internal armed conflict in Guatemala (33% of whom were estimated to be living in Quiché at the time of the study), 44% lived with a lifetime psychiatric disorder according to the ICD-10[22]. Moreover, evidence from other post-conflict areas such as South Sudan, reveal long-term post-traumatic and mental health disorders amongst survivors of conflict situations, which may explain higher proportions in Guatemala in the most affected departments[23]. In addition, criminal organisations and gangs are most active in the urban areas of Guatemala, especially Guatemala City, leading to higher rates of violent crime and extortion which may also impact on mental health[24].

Regardless of reasons, the lower prevalence of disability, does not in any way imply that less attention should be given to these two regions in the context of disability. In fact as discussed below, findings from the case-control study suggest that in poorer, rural areas (predominant in these regions) people with disabilities may face significantly greater challenges in areas such as access to education. Further, of importance to note was that among people with disabilities, both quality of life and participation scores were lowest in these two regions despite the lowest regional prevalence.

Impact of Disability

The findings from this study comparing people with and without disabilities underlined significant restrictions felt by people with disabilities across Guatemala in a range of important life domains. It has also highlighted the heterogeneity of the lived experience of disability and how this was associated with different socio-economic factors as well type of functional limitation.

Survey Results

People with disabilities identified in the survey were more likely to be older, female, poorer, unmarried and less educated than the general population. A third of households in the survey included at least one person with a disability, and these households were larger (average number of household members), poorer, had a higher average age and a higher dependency ratio than households without any members with disabilities. These findings support the theory that people with disabilities, and households including people with disabilities, are generally poorer, more vulnerable and less resilient to shocks compared to people and households without any disabilities[25]. As highlighted in the

qualitative work, the impact of disability extends to the whole family, particularly in situations of extreme poverty and in the absence of safety nets.

Interestingly, given the complex ethnic background of Guatemala, and the documented links between ethnic groups, social exclusion, poverty and the Civil War, disability was not found to be associated with ethnic group.

Case Control Study

Socio-Economics and work

Adults with disabilities were both twice as likely never to have attended school and to be illiterate than adults without disabilities, were almost twice as likely to have never married, and were half as likely to have worked in the last week than adults without disabilities.

Once these findings were stratified, men with disabilities were much less likely to be working than men without disabilities, but women with disabilities did not have lower access to work than women without disabilities. However, only 28% of women with disabilities and 33% of women without disabilities reported working, suggesting that women in Guatemala have lower access to work than both men with (44%) and without (77%) disabilities. These sex differentials are important, and require contextual understanding about sex roles in Guatemala.

In addition, urban/rural stratification showed that people with disabilities in urban areas were much less likely to work than people without disabilities, but that there were no differences amongst those living in rural areas. This suggests that more barriers to employment for people with disabilities may exist in urban settings, where the formal sector is likely to be bigger, than in rural areas that are predominantly agrarian or informal. This finding should not be misunderstood to mean that people with disabilities in rural settings face less hardship, but that capacities and opportunities for employment are different in rural and urban settings, requiring targeted interventions and solutions.

Health

People with disabilities were three times more likely to have experienced a serious health problem in the last 12 months than people without. Limited opportunities to work and more frequent episodes of serious illness increase the likelihood of catastrophic health expenditure: large-scale out-of-pocket expenditure on health that can push a household further into poverty[26]. A 2015 Health Systems Assessment Report by USAID reflects on the impact of the 2014 cancellation of Guatemala's Extension of Coverage (PEC) programme, and the vacuum in free healthcare provision as a result[27].

Photo 7: Testing Vision

Whilst health seeking behaviour, such as whether or not advice was sought and at what type of facility, was similar for people with and without disabilities, people with disabilities also reported more negative experiences including being more likely to feel disrespected or

to find it difficult to understand available information. This highlights the need for a more nuanced understanding of inclusion and accessibility of health services beyond physical infrastructure such as ramps. Attitudinal and informational barriers to health information, and lower quality of experience with health care providers, remain a much under-prioritised area in inclusive health design and policies, and in need of greater emphasis.

Prevention of disability was not a focus of this study. However, this is still an important public health area that should be included in public health programme design. In particular, the Washington Group modules are not validated for infants age 0 – 1 years old, but public health interventions should include a focus on the "first thousand days of life" to ensure adequate identification of children at risk, in addition to monitoring and addressing causes of disability throughout the life course.

Children

Encouragingly, over 80% of children with and without disabilities attended school in urban areas. However in rural areas only 61% of children with disabilities attended compared to 82% of children without disabilities. Amongst children with disabilities, girls and children with physical or cognitive limitations had the lowest access to school. This echoes a recent multi-country study including almost 9,000 children with disabilities which found lower access rates amongst children with physical and cognitive limitations, and supports calls for inclusive education policies to be strengthened in light of the heterogeneity of accessibility and learning needs amongst children with disabilities[28]. All children have a right to education and this study highlights a need to address both disability and sex inequalities in access to education at this early and crucial stage of children's lives, particularly in rural areas. In addition to negative social, emotional and health impacts, exclusion from education can lead to lower employment and earning potential among people with disabilities, making them and their families more vulnerable to poverty.

Children with disabilities were half as likely to live with their biological father than children without disabilities. This supports previous research which has found an association between the stigma of child disability and abandonment of the child and primary caregiver by the biological father, leading to further vulnerability and limited economic potential[29].

Participation, Environment and Quality of Life

Overall, people with disabilities faced higher participation restrictions and environmental barriers compared to people without disabilities across all major activities. These restrictions were particularly large amongst older adults, men with disabilities, those who had never married and those with no formal education. People with disabilities reported overall lower quality of life than people without disabilities, including in the sub-scales of quality of life related to physical health, psychological health, social relationships and the environment. Considering the breadth of findings in this study on the exclusions and barriers faced by people with disabilities in terms of education, employment, health, participation and the environment, the finding that this impacts on Quality of Life is not altogether surprising. Greater coverage of inclusive policies and services in Guatemala are imperative to alleviate these barriers and meet the needs of people with disabilities in a meaningful way.

Differences amongst people with disabilities

Amongst people with disabilities a lower QoL was associated with lower socio-economic status, living in a rural area, or in the North-East and South-East regions. People with disabilities who had not received a formal education were less likely to be working and school attendance was lowest in rural areas. These findings furthers support for the argument that the lived experience of disability is complex and fundamentally interconnected with poverty and structural inequality.

These analyses amongst people with disabilities also highlighted a number of trends in terms of type of disability. For example, children with physical or cognitive limitations had the lowest access to school, whilst adults with physical or cognitive limitations were the least likely to work, and reported the lowest participation and quality of life scores amongst people with disabilities. This may be associated with physical inaccessibility of infrastructure, or to cultural stigma in relation to particular infectious diseases or congenital conditions.

Finally, people with disabilities who were unmarried/not living with a partner were less likely to be working, more likely to experience difficulties with their WASH access and faced higher participation restrictions than other people with disabilities. This may also be related to cultural stigma related to particular disabilities or severity of disability, and a social exclusion that limits options for marital union.

Rehabilitation

Awareness of rehabilitation services among people with disabilities was relatively low and therefore use of the services was therefore also low. This is consistent with previous studies undertaken in Haiti, India and Cameroon[7 30]. 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.

Stakeholder feedback

Four dissemination workshops were held in Guatemala City in March 2017. Sebastian Toledo, CEO of CONADI, strongly advocated the use of study results as an instrument to advocate for full inclusion of people with disabilities in Guatemala. Emphasis was placed on sharing the findings with municipal policy makers and civil societies (particularly DPOs) working at this level, given the devolvement of policy making to municipal bodies. However, the need to support this centrally, including adequate provision of resources and monitoring of implementation of policies, was also considered a priority by stakeholders.

The study findings were endorsed by several high-profile Government officials, including the President of the Parliamentary Congress on Disability, the Vice-Minister of Public health and the Chief of the Ministry of Defence Disability Centre.

The need to create public-private-civil society alliances was encouraged by audiences at the workshops. To truly ensure that the rights of people with disabilities are met in Guatemala, stakeholders must work together.

Finally, the National Statistics Institute of Guatemala were strongly encouraged to include the Washington Group Short Set of questions in the upcoming Guatemala Census 2020.

Strengths and limitations

This was a large national study, which achieved a good response rate and the age and sex distribution was similar to the national population. We used internationally recognised and standardised tools for assessing disability and findings were in-line with other studies using these approaches lending weight to the validity of the data. Using both qualitative and quantitative data together provides a rich picture of disability, more so than using either methodology in isolation.

There were some limitations: The response rate was lower in the Central region, due to higher lack of availability of eligible participants. The age and sex distribution of the study sample was similar to that of the national population, which suggests that we did not over/under-sample particular age groups. However, it is possible that people with disabilities may have been more likely than people without disabilities to be in their households and included in the survey which may have contributed to the higher prevalence in this area. Fewer controls were included in the study than cases due to the high prevalence in the older age group, limiting the number of potential controls. To account for imperfect matching all case/control comparative analyses were adjusted for age, sex and region, as per standard statistical methodology for the control of bias in observational studies[31]. For the case-control study we only included people with disabilities according to the Washington Group questions (not clinical impairments) and people with moderate clinical impairements were eligible as controls. This may have slightly diluted the comparison between people with and without disabilities. However, many other studies comparing people with and wihout disabilities use only the Washington Group questions for their case definition and therefore our methods are comparable. Although much effort was made to include speakers of the most common Mayan languages in the study team, regional dialects and low education may have influenced responses in remote areas. Finally, migrant, transient and institutionalised populations were not included in the sample.

8. Recommendations

Key recommendations from the study include:

- Taking into consideration that 10.2% of the national population, and 31% of all households in Guatemala, include at least one person with a disability, and given the multiple associations between disability and disadvantage identified by ENDIS 2016, inclusion of persons with disabilities is an urgent priority for all public policies and programming.

- Deprivation, no access to safety nets, constrained livelihoods, infrastructural barriers, profound isolation, lower quality of life and low assets are common realities that entrap persons with disability, particularly in rural areas. The provision of safety nets and active inclusion of people with disabilities and their families in existing social programs is imperative.

- The survey should be repeated in approximately five years, in line with international recommendations, to assess change over time and to compare findings with other countries in the region.

- Stakeholders must recognise the differing needs amongst people with disabilities and ensure effective mechanisms to support these. For example, children with disabilities require support in accessing education, older people with disabilities need rehabilitation and other support, and women with disabilities face multiple additional disadvantages.

- Further research on mental illnesses in the Guatemalan population, and assessment of the mental health system is urgently needed to create an evidence-based framework for mental health within the Guatemalan public health system. in particular, efforts are needed to address the sex disparity in the prevalence of anxiety/depression, and in the promotion and resourcing of community mental health programmes.

- A new, evidence-based inclusion plan for patients with disabilities should be created and enacted by the Guatemalan public health system. This plan should address the realization of the rights of people with disabilities at all levels of the public health system, the financing of their healthcare, the provision of assistive devices and supports, and the mitigation of catastrophic medical expenses that they and their families might incur. Moreover, effort is needed in better training of healthcare staff to ensure that people with disabilities seeking healthcare are treated with respect and dignity.

- Livelihoods of people with disabilities should be developed through both governmental and private sector initiatives. Particular focus is needed on addressing the urban/rural disparities identified in this study, and on creation of entrepreneurship and training programmes to support people with disabilities in finding work. In addition, the additional disadvantages faced by women with disabilities (lower access to work than men with and without disabilities) should be combatted by active positive discrimination and affirmative action to support their access to livelihoods.

- The education of children with disabilities should be prioritised through the public education system, particularly in rural areas. A special focus is needed on addressing the sex, disability-type, and urban/rural disparities in education identified in this study, and to promoting the relevant legislation to overturn this.

- The absense of fathers in households with children with disabilities found in this study needs to be addressed through social interventions and programs. Children who have been abandoned by their father should be given social support, for example via the Ministry of Wellbeing.

- Public awareness of the rehabilitation and health services available in Guatemala should be improved, through the dissemination/utilization of the National Directory of Disability Services via the Guatemalan public health system, targeted awareness-raising to segments of the population in which disparities are highest, and decentralization of rehabilitation from

specialty centres to community based rehabilitation. In particular, the approach, 'Modelo Incluyente de Salud' (MIS) promoted by the minister of Health, is an excellent opportunity to strengthen community based approached to rehabilitation, mental health, promotion and prevention.

- Stakeholders must work together to acquire additional funds to fully realise the National Action Plan on realising the Convention on the Rights of Persons with Disabilities already established by CONADI, and to ensure adequate budgeting for inclusion across all government and non-government programmes. The results of this study (both quantitative and qualitative) should be incorporated, along with links to the Sustainable Development Agenda, the WHO Global Disability Action Plan, the WHO GATES project, the Education for All Salamanca Statement and the recommendations of the UNCRPD committee on the implementation of the CRPD in Guatemala.

- The public should be educated to understand their rights and facilitated via Disabled People's Organisations to monitor and challenge public and private actions from the local, municipal and regional levels through departmental and municipal commissions.

- The National Statistical Office (INE), should include questions on disability based on WG questions in all their surveys and disaggregate data by sex and disability.

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Appendix 1a: Washington Group Module Ages 2-4

1	Does (*name*) wear glasses? *If No --> Q3*	O Yes (1) O No (0)
2	When wearing his/her glasses, does (*name*) have difficulty seeing? *(--> Q4)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
3	Does (name) have difficulty seeing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
4	Does (*name*) use a hearing aid? *If No --> Q6*	O Yes (1) O No (0)
5	When using his/her hearing aid(s), does (*name*) have difficulty hearing sounds like peoples' voices or music? *(--> Q7)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
6	Does (*name*) have difficulty hearing sounds like peoples' voices or music?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
7	Does (*name*) use any equipment or receive assistance for walking? *If No --> Q10*	O Yes (1) O No (0)
8	Without using his/her equipment or assistance, does (*name*) have difficulty walking?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
9	When using his/her equipment or assistance, does (*name*) have difficulty walking *(--> Q11)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
10	Compared with children of the same age, does (*name*) have difficulty walking?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
11	Compared with children of the same age, does (*name)* have difficulty picking up small objects with his/her hand?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
12	Does (*name*) have difficulty understanding you?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
13	When (*name*) speaks, does he/she have difficulty being understood by you?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
14	Compared with children of the same age, does (*name*) have difficulty learning things?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
15	Compared with children of the same age, does (*name*) have difficulty playing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
16	Compared with children of the same age, how much does (*name*) kick, bite or hit other children or adults?	O Not at all (0) O More (2) O Same or Less (1) O A Lot More(3)

Appendix 1b: Washington Group Module Ages 5-17

1	Does (*name*) wear glasses? *If No --> Q3*	O Yes (1) O No (0)
2	When wearing his/her glasses, does (*name*) have difficulty seeing? *(--> Q4)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
3	Does (name) have difficulty seeing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
4	Does (*name*) use a hearing aid? *If No --> Q6*	O Yes (1) O No (0)
5	When using his/her hearing aid(s), does (*name*) have difficulty hearing sounds like peoples' voices or music? *(--> Q7)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
6	Does (*name*) have difficulty hearing sounds like peoples' voices or music?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
7	Does (*name*) use any equipment or receive assistance for walking? *If No --> Q10*	O Yes (1) O No (0)
8	Without using 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	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
9	Without using 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	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
10	When using 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	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
11	When using 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 (-->Q14)	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
12	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	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
13	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	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
14	Does (name) have difficulty with self-care such as feeding or dressing him/herself?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
15	When (name) speaks, does he/she have difficulty being understood by people inside of this household?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
16	When (name) speaks, does he/she have difficulty being understood by people outside of this household?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
17	Compared with children of the same age, does (name) have difficulty learning things?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)

18	Compared with children of the same age, does (name) have difficulty remembering things?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
19	How often does (name) seem anxious, nervous or worried?	O Daily (0) O Weekly (1) O Monthly (2) O Few Times a Year (3) O Never (4)
20	How often does (name) seem sad or depressed?	O Daily (0) O Weekly (1) O Monthly (2) O Few Times a Year (3) O Never (4)
21	Compared with children of the same age, how much difficulty does (name) have controlling his/her behaviour?	O None (0) O The same or less (1) O More (2) O A lot more (3)
22	Does (name) have difficulty focusing on an activity that he/she enjoys doing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
23	Does (name) have difficulty accepting changes in his/her routine?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
24	Does (name) have difficulty making friends?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)

Appendix 1c: Washington Group Module Ages 18+

1	Do you wear glasses? *If No --> Q3*	O Yes (1) O No (0)
2	Do you have difficulty seeing, even when wearing your glasses *(--> Q4)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
3	Do you have difficulty seeing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
4	Do you have difficulty clearly seeing someone's face across the room [even if wearing your glasses]?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
5	Do you have difficulty seeing the picture on a coin [even when wearing your glasses]?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
6	Do you use a hearing aid? *If No --> Q8*	O Yes (1) O No (0)
7	Do you have difficulty hearing, even when using a hearing aid(s)? *(--> Q9)*	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
8	Do you have difficulty hearing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
9	Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when using your hearing aid]?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
10	Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when using your hearing aid?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
11	Do you have difficulty walking or climbing steps?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
12	Do you use any equipment or receive help for getting around*? If No --> Q15*	O Yes (1) O No (0)
13	Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block with the use of your aid?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
14	Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks with the use of your aid?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
15	Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [WITHOUT the use of your aid]?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
16	Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [WITHOUT the use of your aid]?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)

17	Do you have difficulty walking up or down 12 steps?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
18	Using your usual language, do you have difficulty, for example understanding or being understood?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
19	Do you use sign language?	O Yes (1) O No (0)
20	Do you have difficulty remembering or concentrating?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
21	Do you have difficulty with self-care, such as washing all over or dressing?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
22	Do you have difficulty raising a 2 litre bottle of water or soda from waist to eye level?	O None (0) O A Lot (2) O Some (1) O Can't Do (3)
23	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 None (0) O A Lot (2) O Some (1) O Can't Do (3)
24	How often do you feel worried, nervous or anxious?	O Daily (0) O Weekly (1) O Monthly (2) O Few Times a Year (3) O Never (4)
25	Do you take medication for these feelings? *If Never to Q24 and No to Q25 --> Q27*	O Yes (1) O No (0)
26	Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	O A Little (0) O A Lot (1) O A lot > A Little (2)
27	How often do you feel depressed?	O Daily (0) O Weekly (1) O Monthly (2) O Few Times a Year (3) O Never (4)
28	Do you take medication for depression? *If Never to Q27 and No to Q28 --> Q30*	O Yes (1) O No (0)
29	Thinking about the last time you felt depressed, how depressed did you feel?	O A Little (0) O A Lot (1) O A lot > A Little (2)
30	In the past three months, how often did you have pain? *If Never --> Q32*	O Never (0) O Some days (1) O Most Days (2) O Every Day (3)
31	Thinking about the last time you had pain, how much pain did you have?	O A Little (0) O A Lot (1) O A lot > A Little (2)

32	In the past three months, how often did you feel very tired or exhausted? *If Never --> END*	O Never (0) O Some days (1) O Most Days (2) O Every Day (3)
33	Thinking about the last time you felt very tired or exhausted, how long did it last?	O Some of the day (0) O Most of the day (1) O All of the day (2)
34	Thinking about the last time you felt this way, how would you describe the level of tiredness?	O A Little (0) O A Lot (1) O A lot > A Little (2)

Appendix 2: Additional Tables

Table a1: Factors associated with school attendance among children with disabilities

	Not attending school		Attending school		Age, sex, location[a] adjusted OR
	N	%	N	%	
Age (years)					
5-8	13	42	28	29	Baseline
9-12	4	13	30	31	3.8 (1.0-14.2)
13-17	14	45	40	41	1.4 (0.5-3.8)
Sex					
Male	10	32	47	48	Baseline
Female	21	68	51	52	0.6 (0.2-1.5)
Socioeconomic status					
1st (poorest)	14	45	18	18	Baseline
2nd	6	19	28	29	2.6 (0.8-8.8)
3rd	11	35	52	53	1.4 (0.4-4.5)
Location					
Rural	26	84	42	43	Baseline
Urban	5	16	56	57	7.4 (2.6-21.3)
Region[a]					
Central	2	6	32	33	
North East	2	6	7	7	
North West	13	42	37	38	
South East	7	23	2	2	
South West	7	23	20	20	
Ethnicity					
Latino/Mix	15	48	47	48	1.0
Mayan	13	42	48	49	1.0 (0.4-2.6)
Functioning domain[b]					
Vision	3	10	14	14	1.7 (0.4-7.2)
Hearing	3	10	7	7	0.9 (0.2-4.5)
Physical	4	13	3	3	0.2 (0.02-1.0)
Cognitive[c]	11	35	12	13	0.3 (0.1-0.9)
Anxiety/depression	19	22	66	77	1.0 (0.4-2.7)
Multiple domains	8	42	11	57	0.4 (0.1-1.5)

[a]Because of small numbers of children in some regions who were not attending school OR have not been calculated and adjusted analysis are adjusted for urban/rural location rather than region. [b]Non mutually exclusive binary variables; [c]Cognitive= at least a lot of difficulties understanding/being understood (communication) and/or with learning

Table a2: Factors associated with having worked in the past week among adults with disabilities

	Not working		Working		Age, sex, region adjusted OR
	N	%	N	%	
Age (years)	78	20	68	35	
18-34	81	21	62	32	
35-49	76	20	42	22	0.8 (0.5-1.4)
50-64	148	39	22	11	0.6 (0.4-1.0)
65+	78	20	68	35	0.1 (0.1-0.2)*
Sex					
Male	110	29	85	44	Baseline
Female	273	71	109	56	0.3 (0.2-0.5) *
Socioeconomic status					
1st (poorest)	85	22	38	20	Baseline
2nd	107	28	56	29	0.8 (0.4-1.4)
3rd	100	26	50	26	0.9 (.6-1.6)
4th (wealthiest)	91	24	50	26	0.9 (0.5-1.6)
Location					
Rural	208	54	103	53	Baseline
Urban	175	46	91	47	1.1 (0.7-1.8)
Region					
Central	96	25	64	33	Baseline
North East	44	11	13	7	0.6 (0.3-1.4)
North West	112	29	71	37	1.0 (0.6-1.7)
South East	38	10	8	4	0.4 (0.2-1.1)
South West	93	24	38	20	0.7 (0.4-1.2)
Ethnicity					
Latino/Mix	201	52	80	41	Baseline
Mayan	169	44	106	55	1.5 (0.9-2.2)
Marital status					
Married/living together	225	59	129	67	Baseline
Widowed/divorced	94	25	25	13	0.9 (0.5-1.7)
Never married/lived with a partner	64	17	39	20	0.6 (0.3-1.0) *
Highest Education					
No school	157	41	51	26	Baseline
Primary	175	46	92	48	1.2 (0.8-1.9)
Secondary or higher	49	13	50	26	1.9 (1.1-3.5) *
Literacy					
Can read well	104	27	60	31	
Can read a little	120	31	41	21	1.0 (0.6-1.5)
Cannot read at all	159	42	93	48	0.7 (0.4-1.2)
Functioning domain[a]					
Vision	128	33	55	28	0.9 (0.6-1.4)
Hearing	66	17	28	14	1.1 (0.6-1.9)
Physical[b]	162	42	49	25	0.6 (0.4-0.9) *
Anxiety/depression[b]	142	37	86	44	1.2 (0.9-1.9)
Communication[c]	34	8	12	6	0.5 (0.-1.1)
Multiple domains[d]	127	33	46	24	0.8 (0.5-1.3)

*significant (p<0.05) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a3: Factors associated with reporting usually coming into contact with feaces when using the toilet among people with disabilities

	Access without contact with Faeces				
	No		Yes		Age, sex, region, SES adjusted OR
	N	%	N	%	
Age (years)					
5-17	43	21	87	17	Baseline
18-49	68	33	221	44	0.6 (0.4-1.0)*
50+	96	46	192	38	0.9 (0.6-1.5)
Sex					
Male	76	37	177	35	Baseline
Female	131	63	323	65	1.0 (0.6-1.5)
Socioeconomic status					
1st (poorest)	49	24	106	21	Baseline
2nd	53	26	145	29	1.1 (0.6-1.8)
3rd	54	26	128	26	0.9 (0.5-1.5)
4th (wealthiest)	51	25	121	24	1.0 (0.6-1.7)
Location					
Rural	113	55	267	53	Baseline
Urban	94	45	233	47	0.9 (0.6-1.3)
Region					
Central	59	29	135	27	Baseline
North East	25	12	41	8	1.2 (0.7-2.1)
North West	60	29	173	35	0.8 (0.5-1.2)
South East	28	14	27	5	2.2 (1.1-4.1)*
South West	35	17	124	25	0.6 (0.4-1.0)
Ethnicity					
Latino/Mix	91	44	246	49	Baseline
Mayan	105	51	238	48	1.0 (0.7-1.5)
Marital status					
Married/living together	88	51	269	62	Baseline
Widowed/divorced	42	24	77	18	1.2 (0.8-2.0)
Never married/lived with a partner	44	25	90	21	1.8 (1.1-3.0)*
Highest Education					
No school	80	39	148	30	1.6 (0.9-2.7)
Primary	92	45	252	51	1.0 (0.7-1.7)
Secondary or higher	34	17	98	20	Baseline
Literacy					
Can read well	98	47	226	45	Baseline

Can read a little	49	24	150	30	0.8 (0.6-1.3)
Cannot read at all	60	29	124	25	1.1 (0.7-1.6)
Functioning domain[a]					
Vision	53	26	147	29	0.8 (0.5-1.2)
Hearing	36	17	68	14	1.3 (0.8-2.0)
Physical[b]	68	33	150	30	1.0 (0.7-1.5)
Anxiety/depression[b]	66	32	188	38	1.6 (1.0-2.7)
Communication[c]	85	41	229	46	0.8 (0.6-1.1)
Multiple domains[d]	60	29	132	26	1.2 (0.8-1.8)

*significant (p<0.05) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a4: Factors associated with reporting being able to use the toilet without assistance among people with disabilities

	Able to use toilet without assistance				
	No		Yes		Age, sex, location[a] adjusted OR
	N	%	N	%	
Age (years)					
5-17	35	20	95	18	Baseline
18-49	58	32	231	44	0.7 (0.4-1.1)
50+	86	48	202	38	1.1 (0.7-1.8)
Sex					
Male	59	33	194	37	Baseline
Female	120	67	334	63	1.3 (0.7-1.8)
Socioeconomic status					
1st (poorest)	37	21	118	22	Baseline
2nd	47	26	151	29	0.9 (0.5-1.5)
3rd	50	28	132	25	0.9 (0.6-1.5)
4th (wealthiest)	45	25	127	24	1.1 (0.7-1.7)
Location					
Rural	96	54	284	54	Baseline
Urban	83	46	244	46	0.8 (0.5-1.3)
Region[a]					
Central	54	30	140	27	Baseline
North East	14	8	52	10	0.6 (0.3-1.2)
North West	57	32	176	33	0.8 (0.5-1.3)
South East	22	12	33	6	1.6 (0.8-3.0)
South West	32	18	127	24	0.6 (0.4-1.0)
Ethnicity					
Latino/Mix	72	40	265	50	Baseline
Mayan	98	55	245	46	0.7 (0.5-1.2)
Marital status					
Married/living together	69	45	288	63	Baseline
Widowed/divorced	43	28	76	17	**1.7 (1.0-2.8)**

Never married/lived with a partner	42	27	92	20	**2.3 (1.4-3.9)**
Highest Education					
No school	64	36	164	31	1.2 (0.7-2.1)
Primary	82	46	262	50	1.0 (0.6-1.6)
Secondary or higher	31	18	101	19	Baseline
Literacy					
Can read well	80	45	244	46	Baseline
Can read a little	46	26	153	29	1.0 (0.6-1.6)
Cannot read at all	53	30	131	25	1.2 (0.7-1.8)
Functioning domain[a]					
Vision	48	27	152	29	0.8 (0.6-1.3)
Hearing	28	16	76	14	1.0 (0.6-1.6)
Physical[b]	65	36	153	29	1.3 (0.8-1.9)
Anxiety/depression[b]	23	13	46	9	1.6 (0.9-2.8)
Communication[c]	74	41	240	45	0.8 (0.6-1.2)
Multiple domains[d]	56	31	136	26	1.2 (0.8-1.8)

NB: Higher score=better QOL *significant (p<0.05) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a5: Factors associated with participation among people with disabilities

	N	Mean participation score (95% CI)	Age, sex, region, SES adjusted P-value
Age (years)			
5-17	123	85.6 (81.8-89.2)	Baseline
18-49	284	83.7 (81.4-85.9)	0.15
50+	282	73.1 (70.2-76.0)	<0.001
Sex			
Male	243	76.5 (73.3-79.7)	Baseline
Female	446	81.4 (79.5-83.4)	<0.001
Socioeconomic status			
1st (poorest)	152	77.3 (73.5-81.2)	Baseline
2nd	192	78.2 (74.9-81.4)	0.92
3rd	175	81.2 (78.1-84.2)	0.49
4th (wealthiest)	170	82.0 (78.5-85.5)	0.85
Location			
Rural	369	76.8 (74.3-79.3)	Baseline
Urban	320	83.0 (80.7-85.3)	0.12
Region			
Central	191	85.9 (83.3-88.6)	Baseline
North East	64	70.5 (63.1-77.8)	<0.001

North West	230	80.6 (77.9-83.2)	0.06
South East	54	59.0 (50.8-67.2)	<0.001
South West	150	81.7 (78.5-84.8)	0.15
Ethnicity			
Latino/Mix	329	81.0 (78.6-83.4)	Baseline
Mayan	335	78.5 (75.9-81.0)	0.68
Marital status			
Married/living together	351	81.9 (79.7-84.1)	Baseline
Widowed/divorced	116	72.5 (68.1-77.4)	0.03
Never married/lived with a partner	131	76.6 (72.2-80.9)	<0.001
Highest Education			
No school	222	71.1 (67.8-74.5)	Baseline
Primary	334	82.3 (80.4-84.6)	<0.001
Secondary or higher	130	88.0 (85.2-90.6)	<0.001
Literacy			
Can read well	314	82.0 (79.5-84.5)	Baseline
Can read a little	194	80.7 (77.8-83.6)	0.6
Cannot read at all	181	74.5 (70.9-78.2)	0.1
Functioning domain[a]			
Vision	179	77.1 (73.7-80.5)	0.87
Hearing	90	75.0 (70.2-78.9)	0.86
Physical[b]	208	67.5 (63.7-71.3)	<0.001
Anxiety/depression[b]	224	80.8 (78.1-83.5)	0.31
Communication[c]	44	57.8 (48.6-66.9)	<0.001
Multiple domains[d]	167	66.9 (62.7-71.1)	<0.001

NB: Lower score=greater participation restrictions *significant (p<0.05) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a6: Factors associated with seeking care for a serious health problem in the past 12 months among people with disabilities

	Sought				
	No		Yes		Age, sex, location[a] adjusted OR
	N	%	N	%	
Age (years)					
5-17	4	5	34	13	Baseline
18-49	35	48	93	37	0.3 (0.1-1.0)*
50+	41	51	127	50	0.4 (0.1-1.1)
Sex					
Male	32	40	87	34	Baseline
Female	48	60	167	66	1.3 (0.7-2.4)
Socioeconomic status					
1st (poorest)	23	29	47	19	Baseline
2nd	32	40	62	24	0.2 (0.1-0.6)*
3rd	16	20	67	26	0.2 (0.1-0.5)*
4th (wealthiest)	9	11	78	31	0.5 (0.2-1.2)
Location					
Rural	54	68	124	49	Baseline
Urban	26	33	130	51	1.5 (0.8-3.2)
Region[a]					
Central	17	21	79	31	Baseline
North East	9	11	26	10	1.0 (0.4-2.7)
North West	28	35	71	27	1.0 (0.5-2.2)
South East	5	6	24	9	1.9 (0.6-6.0)
South West	21	26	54	21	0.8 (0.4-1.8)
Ethnicity					
Latino/Mix	41	52	107	44	Baseline
Mayan	38	48	136	56	1.0 (0.6-1.9)
Marital status					
Married/living together	51	67	137	61	Baseline
Widowed/divorced	11	14	52	23	1.5 (0.7-3.4)
Never married/lived with a partner	14	18	42	18	0.8 (0.3-1.7)
Highest Education					
No school	35	44	77	34	Baseline
Primary	39	49	131	52	0.6 (0.2-1.7)
Secondary or higher	6	8	43	17	0.8 (0.2-2.2)
Literacy					
Can read well	31	39	121	46	Baseline
Can read a little	26	33	73	29	0.9 (0.5-1.8)
Cannot read at all	23	29	60	24	1.0 (0.5-2.1)
Functioning domain[a]					
Vision	48	27	152	28	1.1 (0.6-2.1)
Hearing	13	16	35	14	1.1 (0.5-2.4)
Physical[b]	28	35	105	41	1.6 (0.9-2.9)
Anxiety/depression[b]	1	1	32	10	-
Communication[c]	39	49	122	48	0.8 (0.5-1.4)
Multiple domains[d]	26	33	91	36	1.5 (1.8-2.7)

*significant (p<0.05) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a7: Factors associated with quality of life adults with disabilities

	N	Mean Qol Score (95% CI)	Age, sex, region, SES adjusted P-value
Age (years)			
18-34	146	47.3 (45.2-49.4)	Baseline
35-49	143	48.1 (46.0-50.2)	0.85
50-64	118	46.4 (44.1-48.7)	0.58
65+	170	43.9 (42.2-45.6)	0.09
Sex			
Male	232	46.9 (45.2-48.6)	Baseline
Female	427	47.6 (46.4-48.7)	0.58
Socioeconomic status			
1st (poorest)	141	43.3 (41.3-45.3)	Baseline
2nd	188	45.3 (43.6-47.1)	<0.001
3rd	169	48.1 (46.3-49.9)	<0.001
4th (wealthiest)	161	52.6 (50.6-54.5)	0.001
Location			
Rural	355	44.9 (43.6-46.2)	Baseline
Urban	304	50.2 (48.8-51.7)	0.05
Region			
Central	183	51.0 (49.2-52.8)	Baseline
North East	62	43.4 (39.8-46.9)	0.004
North West	213	46.9 (45.3-48.5)	0.616
South East	52	39.6 (36.0-43.1)	0.001
South West	149	48.0 (46.1-49.9)	0.388
Ethnicity			
Latino/Mix	312	46.4 (45.0-47.8)	Baseline
Mayan	322	48.5 (47.1-49.9)	0.24
Marital status			
Married/living together	357	47.0 (45.7-48.2)	Baseline
Widowed/divorced	119	44.4 (42.2-46.6)	0.27
Never married/lived with a partner	134	48.4 (45.9-50.8)	0.55
Highest Education			
No school	214	44.1 (42.4-45.8)	Baseline
Primary	310	46.7 (45.3-48.1)	0.73
Secondary or higher	132	54.3 (52.2-56.4)	<0.001
Literacy			
Can read well	299	49.8 (48.4-51.2)	Baseline
Can read a little	184	46.3 (44.6-48.1)	0.19
Cannot read at all	176	44.3 (42.4-46.2)	0.17

Functioning domain[a]			
Vision	183	46.1 (44.2-48.0)	0.85
Hearing	94	45.6 (43.3-48.9)	0.41
Physical[b]	211	44.1 (42.3-45.9)	0.005
Anxiety/depression[b]	46	39.4 (35.4-43.4)	<0.001
Communication[c]	228	44.6 (42.9-46.2)	<0.001
Multiple domains[d]	173	42.3 (40.4-44.3)	<0.001
Age of onset*			
Birth	64	47.9 (44.4-51.3)	Baseline
Childhood (0-17)	133	48.7 (46.5-50.8)	0.97
Working age (18 – 59)	251	46.1 (41.9-46.7)	0.66
Retirement age (60 +)	99	44.2 (48.9-53.2)	0.19

*significant ($p<0.05$) [a]Non-mutually exclusive binary variables: subjects may have more than one significant functional limitation. For each of the 5 domains this analysis compares, in turn, people with a difficulty in one domain (e.g. vision) to people without a difficulty in that corresponding domain (people without vision difficulties); [b]Difficulties with walking or with upper body [c]Difficulties being understood/understanding [d]People with reported difficulties in more than one functional domain (e.g. hearing and vision)

Table a8: Clinical Impairments without Missing Data Extrapolations

	All ages		5-17		18-49		50+	
	n	%	n	%	n	%	n	%
Any Clinical Impairment	1223	9.4%	58	1.3%	589	10.6%	576	28.3%
Male	408	6.8%	27	1.2%	150	6.4%	231	24.5%
Female	815	11.6%	31	1.4%	439	13.5%	345	31.6%
Any Visiual Impairment	119	0.9%	2	0.05%	32	0.6%	85	4.2%
Male	49	0.8%	1	0.05%	14	0.6%	34	3.6%
Female	70	1.0%	1	0.05%	18	0.6%	51	4.7%
Any Hearing Impairment	273	2.1%	22	0.5%	71	1.3%	180	8.8%
Male	132	2.2%	11	0.5%	25	1.1%	96	10.2%
Female	141	2.0%	11	0.5%	46	1.4%	84	7.7%
Any Physical Impairment	520	4.0%	33	0.8%	209	3.8%	278	13.7%
Male	179	3.0%	15	0.7%	58	2.5%	106	11.2%
Female	341	4.8%	18	0.8%	151	4.7%	172	15.8%
All Depression	570	7.5%	-		357	6.4%	213	10.5%
Male	154	4.7%	-		73	3.1%	81	8.6%
Female	416	9.6%			284	8.8%	132	12.1%

Appendix 3: Regions, Departments and Municipalities of Guatemala

Central					
1	Guatemala				
	Amatitlán				
	Chinautla				
	Guatemala				
	Mixco				
	Petapa				
	San José Pinula				
	San Juan Sacatepéquez				
	San Pedro Ayampuc				
	Santa Catarina Pinula				
	Villa Canales				
	Villa Nueva				
North East					
2	Baja Verapaz		San Juan Chamelco		Sayaxché
	Cubulco		San Pedro Carchá	5	Izabal
	Purulhá		Santa Catarina la Tin		El Estor
	Rabinal		Senahú		Livingston
	Salamá		Tactic		Los Amates
	San Miguel Chicaj	4	Petén		Morales
3	Alta Verapaz		Dolores		Puerto Barrios
	Chisec		La Libertad	6	Zacapa
	Cobán		Poptún		Río Hondo
	Lanquín		San Benito		Teculután
	Panzós		San José		acapa
	San Cristóbal Verapaz		San Luis		
North West					
7	Totonicapán		San Miguel Ixtahuacán		San Gaspar Ixchil
	Momostenango		San Pablo		San Mateo Ixtatán
	San Cristobal Totonic		San Pedro Sacatepéque		San Miguel Acatán
	San Francisco El Alto		San Rafael Pié de La		San Sebastián Coatán
	Santa María Chiquimul		Tajumulco		San Sebastián Huehuet
	Totonicapán		Tejutla		Santa Ana Huista
8	San Marcos	9	Huehuetenango		Santa Eulalia
	Catarina		Barrillas		Santiago Chimaltenang
	Concepción Tutuapa		Chantla		Soloma
	IIxchiguán		Huehuetenango	10	Quiché
	Malacatán		Ixtahuacán		Chajul
	San Antonio Sacatepéq		La Democracia		Chicamán
	San Cristóbal Cucho		Malacatancito		Chichicastenango
	San Marcos		Nentón		Cunén

	Ixcán				
	Nebaj				
	San Andrés Sajcabajá				
	San Juan Cotzal				
	Santa Cruz del Quiché				
	Uspantán				
			South East		
11	El Progreso		Santa Cruz Naranjo		Jalapa
	Guastatoya		Santa María Ixhuatán		Mataquescuintla
	San Agustín Acasaguas		Santa Rosa de Lima		Monjas
	San Antonio La Paz		Taxisco		San Pedro Pinula
	Sanarate	13	Chiquimula	15	Jutiapa
	Sansare		Camotán		Asunción Mita
12	Santa Rosa		Chiquimula		Atescatempa
	Barberena		Concepción Las Minas		Conguaco
	Casillas		Ipala		Jalpatagua
	Chiquimulilla		Jocotán		Jutiapa
	Cuilapa		Olopa		San José Acatempa
	Guazacapán		San José La Arada		Santa Catarina Mita
	Nueva Santa Rosa	14	Jalapa		Yupiltepeque
			South West		
16	Sacatepéquez		Escuintla		San Martín Sacatepéqu
	Alotenango		La Gomera		San Mateo
	Pastores		Nueva Concepción	21	Suchitepéquez
	San Antonio Aguas Cal		Palín		Chicacao
	San Miguel Dueñas		Santa Lucía Cotzumalg		Cuyotenango
	Santiago Sacatepéquez	19	Sololá		Mazatenango
	Sumpango		San Antonio Palopó		Samayac
17	Chimaltenango		San Pedro La Laguna		San Antonio Suchitepé
	Chimaltenango		Santiago Atitlán		San Lorenzo
	Comalapa		Sololá		Santo Tomás La Unión
	Parramos	20	Quezaltenango	22	Retalhuleu
	Patzún		Cantel		Champerico
	Pochuta		Coatepeque		El Asintal
	San Andrés Itzapa		Génova		Retalhuleu
	San José Poaquil		Ostuncalco		San Andrés Villa Seca
18	Escuintla		Quetzaltenango		