



# GUATEMALA NATIONAL DISABILITY STUDY (ENDIS 2016) SUMMARY REPORT



Investigators:

- Dr. Carlos Dionicio, Conadi
- Dr. Shaun Grech ,Director, The Critical Institute
- Islay Mactaggart, London School of Hygiene & Tropical Medicine
- Jonathan Naber, London School of Hygiene & Tropical Medicine
- Dr. Ana Rafaela Salazar de Barrios, University of San Carlos, Guatemala
- Gonna Rota, CBM
- Sarah Polack, London School of Hygiene and Tropical Medicine

Project Partners:

- CONADI (National Council on Disability), Guatemala
- CBM Latin America Regional Office
- UNICEF Guatemala

CONADI Technical Team:

- Instituto Nacional de Estadística -INE-, Guatemala
- Dr. Mario Paúl Melgar Méndez , Investigador Independiente, Guatemala
- Junta Directiva periodo 2015-2016, CONADI
- Dra. Ana Leticia Pons Gudiel, CONADI
- Lic. Sebastián Toledo, CONADI
- Lic. Rafael Cañas Castillo, CONADI
- Licda. Indra Molina Muñoz, CONADI
- Licda. Rosa Mery Mejía, CONADI

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## Introduction

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 2016) 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

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 cultural, ideological, and social interpretations and responses to disability; to provide insight into the disability and poverty relationship and examine social, political, and economic dimensions of this.



*Photo 1: Testing for Hearing Impairment*

## 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 instruments ask about difficulties in different functional domains, for example “how much difficulty do you have with seeing” with four response options: ‘no’ ‘some’ ‘a lot’ of difficulty or ‘cannot do’. Table 1 shows the different domains included for different age groups.
- 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 tested.

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.

### Nested case-control study

All participants aged  $\geq 5$  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 of the same age, sex and cluster without a disability ('controls') was also selected. Participants were interviewed about socio-demographics, socio-economic indicators, work, 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 study

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>

<b>Children aged 2 - 4</b>	<b>Children aged 5 -17</b>	<b>Adults aged 18+</b>
Seeing	Seeing	Seeing
Hearing	Hearing	Hearing
Mobility	Mobility	Mobility
Communicating	Communicating	Communicating
Learning	Learning	Self Care
Behaviour	Behaviour	Upper body strength
Playing	Remembering	Cognition
Fine Motor	Concentrating	Anxiety and Depression
Self Care	Accepting Change	
	Relationships	
	Anxiety and Depression	

## 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 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 (Table 2).
- There were regional differences in estimated prevalence with the highest prevalence in Central and North West and lowest in North East and South East.

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

<sup>a</sup> Significant difference in prevalence by sex (p<0.05)

### Prevalence by functional domain

	Children 2 - 17		Adults 18+	
	Total (n=5,469)		Total (n=7,603)	
	N	% (95% CI)	N	% (95% CI)
<b>Seeing<sup>a</sup></b>	26	0.5 (0.3 – 0.7)	322	4.2 (3.7 – 4.8)
<b>Hearing<sup>a</sup></b>	35	0.6 (0.5 – 0.9)	301	4.0 (3.5 – 4.5)
<b>Mobility<sup>a</sup></b>	57	1.0 (0.8 – 1.4)	610	8.0 (7.1 – 9.1)
<b>Anxiety/Depression<sup>ac</sup></b>	109	2.5 (2.0 – 3.1)	705	9.3 (8.4 – 10.3)
<b>Self-Care<sup>c</sup></b>	16	0.4 (0.2 – 0.6)	88	1.2 (0.9 – 1.4)
<b>Communicating</b>	38	0.7 (0.5 – 1.0)	65	0.9 (0.6 – 1.2)
<b>Upper body strength</b>		-	134	1.8 (1.4 – 2.2)
<b>Cognition</b>		-	177	2.3 (1.9 – 2.8)
<b>Learning</b>	3	0.05 (0.02 – 0.2)		-
<b>Remembering<sup>c</sup></b>	2	0.05 (0.01 – 0.2)		-
<b>Concentrating<sup>c</sup></b>	12	0.3 (0.2 – 0.5)		-
<b>Playing<sup>b</sup></b>	1	0.09 (0.01 – 0.7)		-
<b>Behaviour</b>	39	0.7 (0.5 – 1.0)		-
<b>Fine Motor<sup>b</sup></b>	2	0.2 (0.05 – 0.8))		-
<b>Accepting Change<sup>c</sup></b>	38	0.9 (0.6 – 1.2)		-
<b>Relationships<sup>c</sup></b>	46	1.0 (0.8 – 1.4)		-

<sup>a</sup>Includes both significant reported functional limitation and/or significant clinical impairment; <sup>b</sup>Children 2 – 4 only <sup>c</sup>Children 5 - 17 only

- 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%).
- Defining disability according to the Washington Group Questions only (and not including the clinical screens) the all-age prevalence of disability would be 9.3% (children 2-17 years: 4.7%, adults 18=49 years: 6.2%, adults ≥50 years 17.7%). These numbers should be used when comparing the findings with other studies using the Washington Group tools only.

### Households with members with disabilities

- Nearly a third (31%) of 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 a higher dependency ratio<sup>1</sup> 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.

### Education

- In rural areas, only 61% of children with disabilities were attending school, which was significantly lower than for 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.

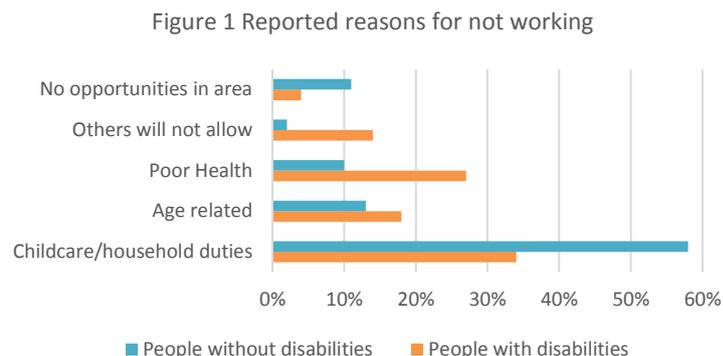
### Work and Employment

- 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%).

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<sup>1</sup> A ratio of the number of dependents (age 0 – 14 or 65+) to independents (age 15 – 64) in the household

- 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 (Figure 1)
- 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%).



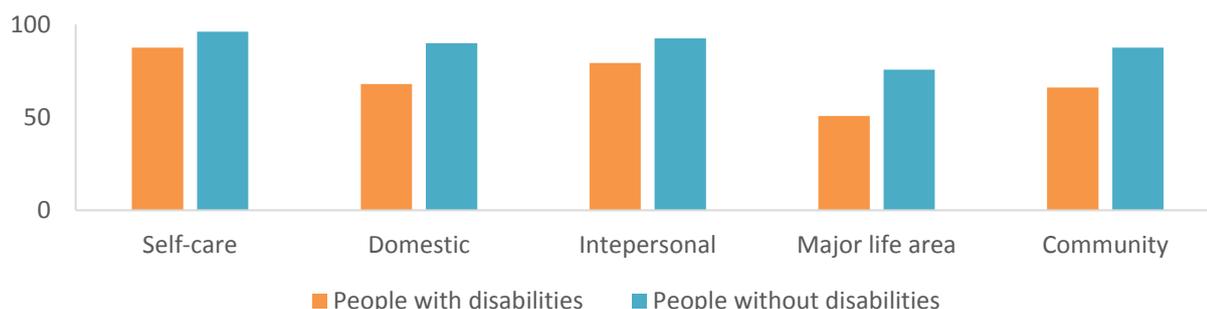
**Water, Sanitation and Hygiene**

- Access to improved<sup>2</sup> 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 environments**

- People with disabilities experienced greater participation restrictions compared to people without disabilities in different life areas (see figure 2).
- People with disabilities reported greater barriers across 12 different environmental domains across (Table 4).

Figure 2. Mean participation scores<sup>3</sup> (≥50 years)<sup>a</sup>



NB Lower scores=greater participation restrictions. <sup>a</sup>Presented for 50+ years but similar trends were also seen for younger age groups.

<sup>2</sup> 'Improved' defined according to the WHO/UNICEF Joint Monitoring Programme as water source being protected from outside contamination, and the sanitation facility separating human excreta from human contact. (see wssinfo.org)

<sup>3</sup> Measured using scales adapted from SINTEF Living Standards surveys see [www.sintef.no/en/](http://www.sintef.no/en/) (permission granted)

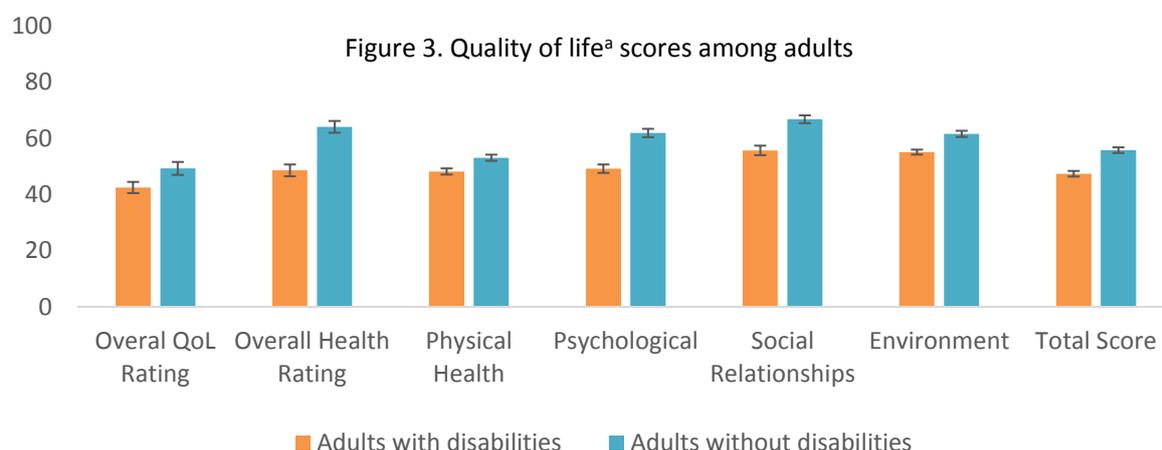
**Table 4: Frequency of built and natural environment created barriers among cases and controls**

	5- 17 years		18-49 years		50+ years	
	Mean scores <sup>a</sup>					
Environmental Domains <sup>3</sup>	People with disabilities n=129	People without disabilities n=113	People with disabilities n=288	People without disabilities n=234	People with disabilities n=290	People without disabilities n=118
Transport	4.3	4.5	3.8	4.3*	3.9	4.3*
Natural environment	4.4	4.7*	4.2	4.6*	3.8	4.5*
Surroundings	4.3	4.7*	4.2	4.6*	4.1	4.5*
Format of information	4.4	4.7*	4.2	4.4*	4.1	4.4*
Availability of health care services	4.3	5.0	4.0	4.3*	3.9	4.1
Availability of assistance at home	4.4	4.7*	4.2	4.4*	4.2	4.5*
Availability of assistance at school/work	4.5	4.8*	4.4	4.6*	4.4	4.8*
Other people's attitudes (at home)	4.3	4.7*	4.3	4.5*	4.6	4.7
Other people's attitudes (at school/work)	4.5	4.8*	4.6	4.7	4.8	4.8
Prejudice and discrimination	4.5	4.8*	4.4	4.6*	4.5	4.6
Policies and rules (Organisations)	1.5	1.7	1.4	1.7*	1.3	1.5*
Government programmes and policies	4.8	5.0*	4.8	4.8	4.8	4.8

<sup>a</sup>Mean score for 12 questions about the frequency at which elements of the built and natural environment created barriers. Lower score reflects worse environmental barriers)

### Quality of life

- Quality of life scores were significantly poorer for people with disabilities compared to people without disabilities across all sub-scales (figure 3)



<sup>a</sup>Quality of life measured using the WHOQOL; NB: Lower score denotes poorer QoL

## Health

- People with disabilities were significantly more likely to have reported a serious health problem in the past 12 months (47%) compared to people without disabilities (23%).
- People with disabilities were significantly more likely to report being disrespected (9% vs 4%) and to find it difficult to understand information given to them at health centres (22% vs 14%).
- Women of reproductive age (15-49 years) with disabilities were less likely to have sought antenatal care in their last pregnancy (87% vs 77%). 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 (81% vs 60%).
- 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.

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

## Differences amongst people with disabilities

It is also important to consider differences in access to and experiences of education, livelihoods, healthcare etc. *amongst* people with disabilities. For example, in this study among adults with disabilities the likelihood of working was significantly lower amongst women compared to men, quality of life was lowest amongst people with disabilities who were poorer, or lived in rural areas. Among children with disabilities, school attendance was lowest for children with significant limitations in physical and cognitive functioning. Please refer to the Main Report (<http://disabilitycentre.lshtm.ac.uk>) for full analysis amongst people with disabilities.

## 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, infrastructural barriers and profound isolation
- Lack of access to safety nets is a key concern, which must be addressed

*"..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)*

## Key Recommendations

- Active inclusion of people with disabilities and their families in existing social programs is imperative to meet their needs and realise their rights under the UNCRPD
- Advocacy at the national level must focus on the development of inclusive policies and appropriate financing for this
- Engagement at the municipal level is imperative to ensure that inclusive programmes are developed, implemented and evaluated
- Stakeholders must recognise and plan for the differing needs amongst people with disabilities and ensure that effective support mechanisms are in place. This includes social protection, safety nets and awareness of the implications of disability on the lives of people with disabilities living in poverty
- Effective policies and programmes should also recognise that disability affects households, rather than individuals
- Mental health should be provided equal importance to physical health and community approaches to supporting people with mental health conditions

*"Knowing how many [people with disabilities] we are, and where we are, makes this historically excluded sector visible on the country agenda, and focuses the State on meeting the requirements of this population. ENDIS 2016 is an instrument that we can use for advocacy to promote concrete actions and the creation of programs that guarantee the rights of the population with disability living in exclusion and vulnerability." – Sebastián Toledo, CEO of the Guatemala National Council on Disability (CONADI)*