



Guatemala National Disability Study (ENDIS 2016)

Dr. Islay Mactaggart

Assistant Professor in Disability and Global Health
International Centre for Evidence in Disability
London School of Hygiene & Tropical Medicine



ENDIS 2016

International
Centre for Evidence
in Disability

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



National Survey of Disability in Guatemala 2016 (Encuesta Nacional De Discapacidad – ENDIS)

Project duration: January – December 2016

Research Support:
Dr. Sarah Polack – Associate Professor, LSHTM
Dr. Islay Mactaggart – Assistant Professor, LSHTM
Dr. Shaun Grech – Director, The Critical Institute

Project Partners:
CONADI (National Council on Disability), Guatemala
INE (National Statistics Office), Guatemala
CBM Latin America
UNICEF Guatemala

Project Funders:
CBM Latin America Regional Office
CONADI
UNICEF Guatemala

Study aims

1. To estimate the national and regional disability prevalence among adults and children in Guatemala
2. To explore the impact of disability on participation, quality of life, socio-economic status, health and opportunities for education and work and water, sanitation & hygiene
3. 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



1. National population-based survey of disability to determine prevalence and characteristics of disability

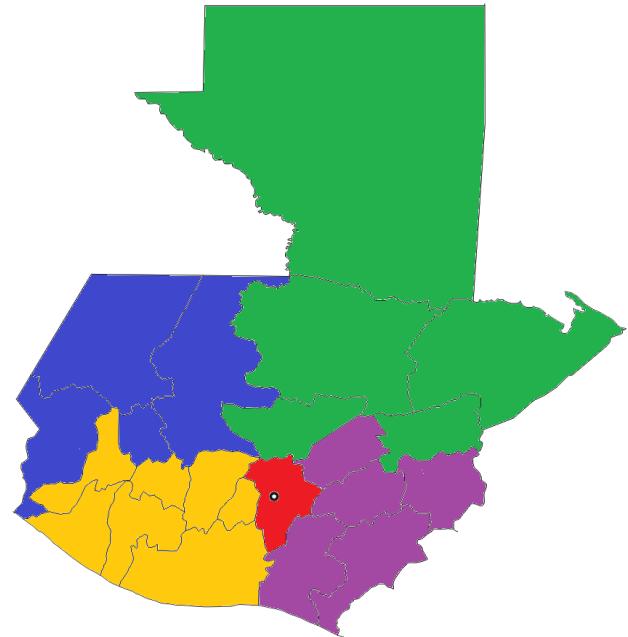
2. Nested Case-Control study comparing people with and without disabilities in key life areas

3. Qualitative study to unpack the contextual understanding of disability in Guatemala



Survey: sampling

- Five broad regions
- Sample size: 13,800
- Selection of clusters (INE): 276 clusters randomly selected (56 per region)



Selection of households



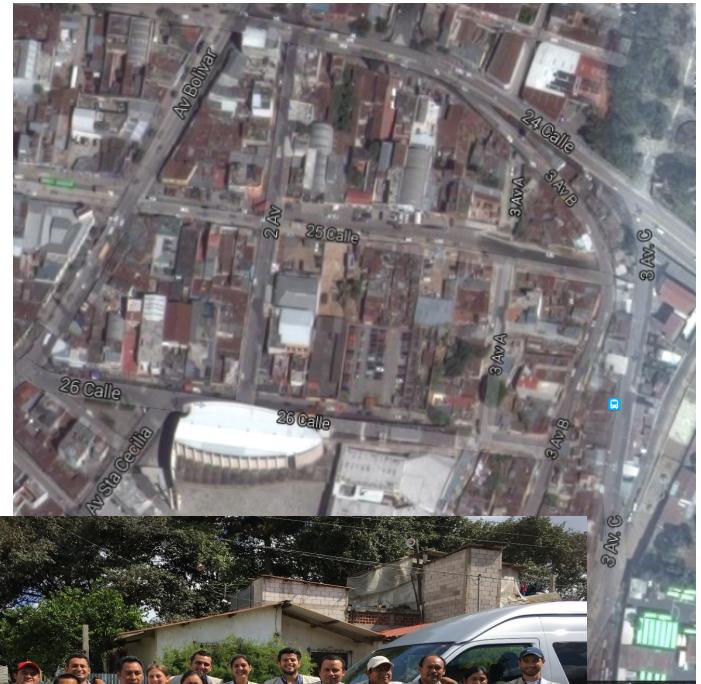
50 people per cluster (aged 2+) selected using compact segment sampling

Community sensitisation

- Appropriate govt. representatives
 - Community leaders of selected clusters
 - Village guides

Enumeration

- Informed consent
 - Household roster (demographics, SES)



1. Disability screening

1. Self-reported functioning:

- Washington Group Extended Set on Functioning for adults aged ≥ 18 years
- UNICEF/WG Extended Set on Functioning for children aged 2-17 years

2. Clinical impairments:

- vision, hearing, mobility, depression

Mobile Data Collection in Surveys

International
Centre for Evidence
in Disability

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



- Growing interest and availability of mobile methodologies for data collection
 - Real time data entry
 - Real time data transfer
 - In built data validation and work flow
 - Standardisation
 - Innovations in mobile tools for impairment screening



2. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing
- Hearing
- Walking
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- *Behaviour**
- *Concentrating**
- *Relationships**

* Children only

3. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing
- Hearing
- Walking
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- *Behaviour**
- *Concentrating**
- *Relationships**



Age 5+ If 'some difficulty' / 'a lot of difficulty' or
cannot do' → relevant clinical impairment screen

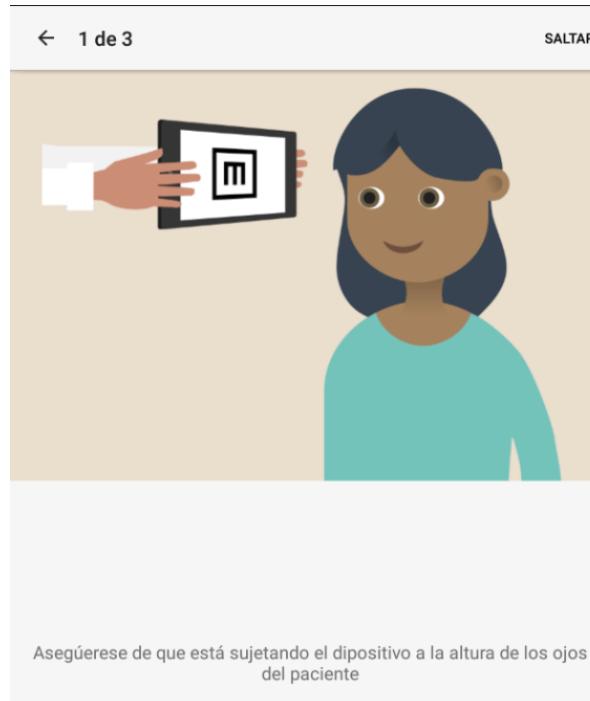
* Children only

4. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing →
- Hearing
- Walking
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- *Behaviour**
- *Concentrating**
- *Relationships**

Vision Test using Peek



* Children only

5. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing
- Hearing →
- Walking
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- Behaviour*
- Concentrating*
- Relationships*

Hearing Test using HearTest



Presione el botón si oye un sonido.

Playing 1000Hz at 40dB



* Children only

6. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing
- Hearing
- Walking →
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- Behaviour*
- Concentrating*
- Relationships*

Physical Performance Test using PPT



Aplicación ENADI

Copie estas imágenes (1er intento)



BOCETO

1er intento (segundos)

Tiempo de redondeo al más cercano a 0,5 segundos

Copie estas imágenes (2do intento)

BOCETO

2do intento (segundos)

Tiempo de redondeo al más cercano a 0,5 segundos

Punteo por Rapidez

≤ 10 sec (4 puntos)

* Children only

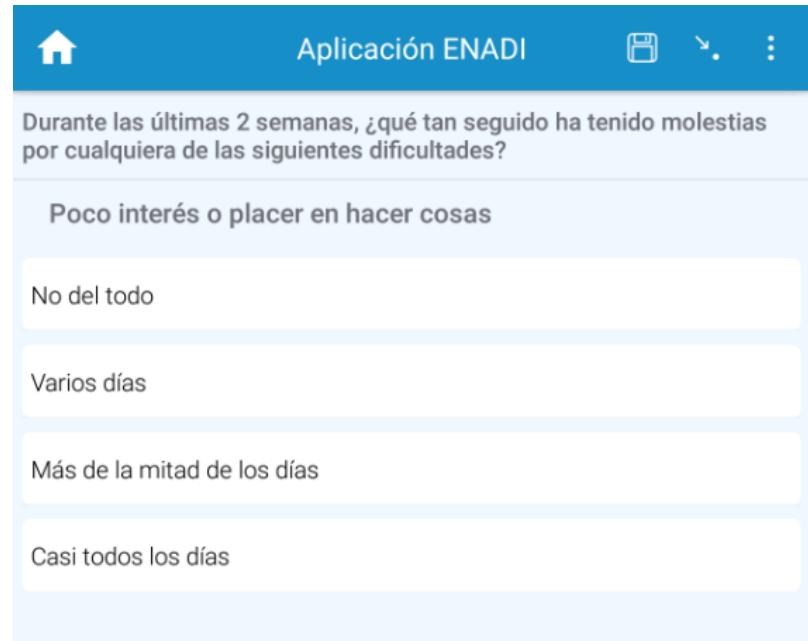
7. Disability screening

1. Self reported difficulty (none, some, a lot, cannot do)

- Seeing
- Hearing
- Walking
- Anxiety
- Depression
- Self care
- Upper body strength
- Cognition
- Communication
- *Behaviour**
- *Concentrating**
- *Relationships**



Age 18+ If 'some difficulty' / 'a lot of difficulty' or
cannot do' **Clinical Depression Test using PHQ9**



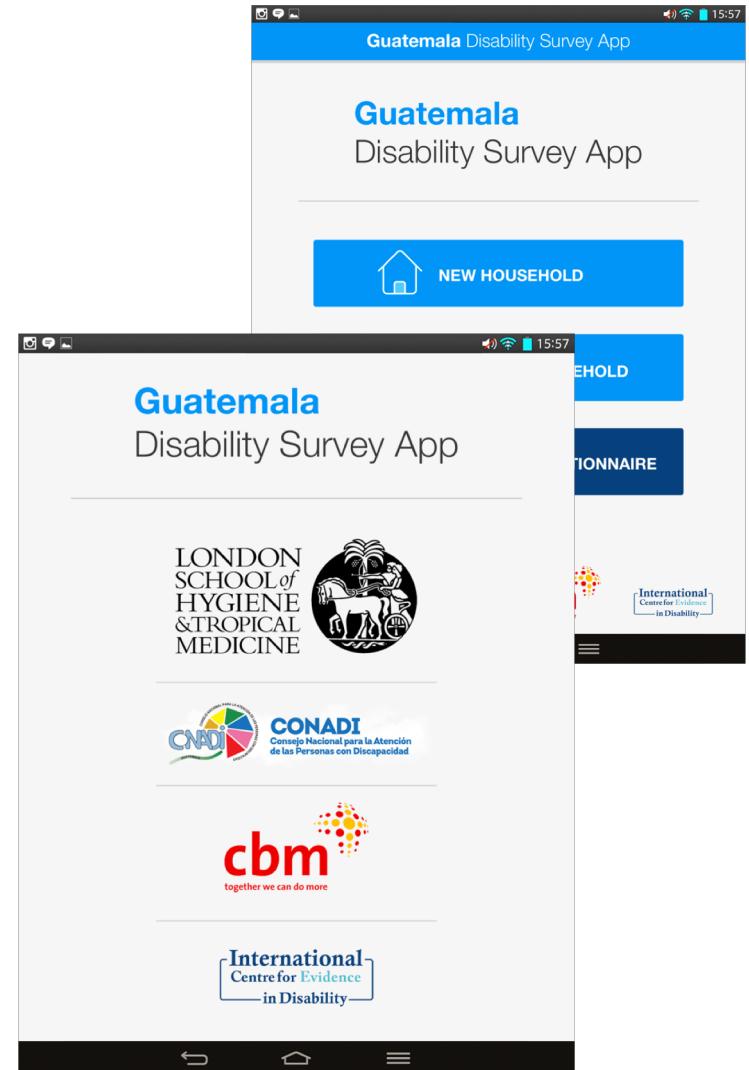
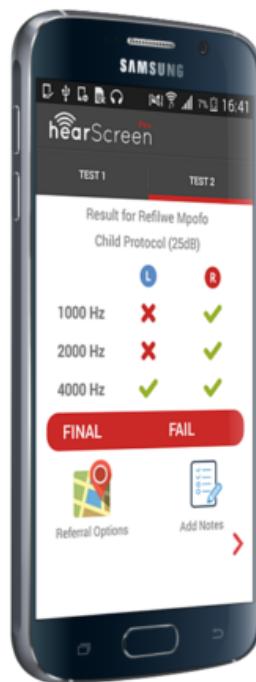
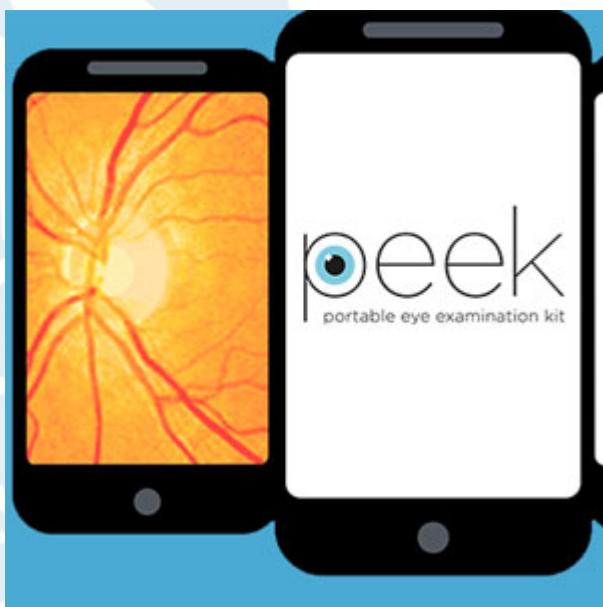
The screenshot shows a mobile application interface for the ENADI application. The top bar is blue with the text "Aplicación ENADI" and icons for home, file, back, and more. The main screen asks: "Durante las últimas 2 semanas, ¿qué tan seguido ha tenido molestias por cualquiera de las siguientes dificultades?". Below this, there is a list of symptoms with dropdown menus for response levels: "Poco interés o placer en hacer cosas" with options "No del todo", "Varios días", "Más de la mitad de los días", and "Casi todos los días".

* Children only

ENDIS 2016



- Bespoke mobile data collection tool developed by UPT
- Integrates PEEK and HearTest



Definition of disability

“A lot of difficulty” or more in at least one of the core WG domains

OR

One or more significant clinical impairment (vision, hearing, physical, depression)

Nested case control study

- Cases: people with disabilities identified in the survey
- Controls: people without disabilities who are age, sex and cluster matched to cases

Interviewed about:

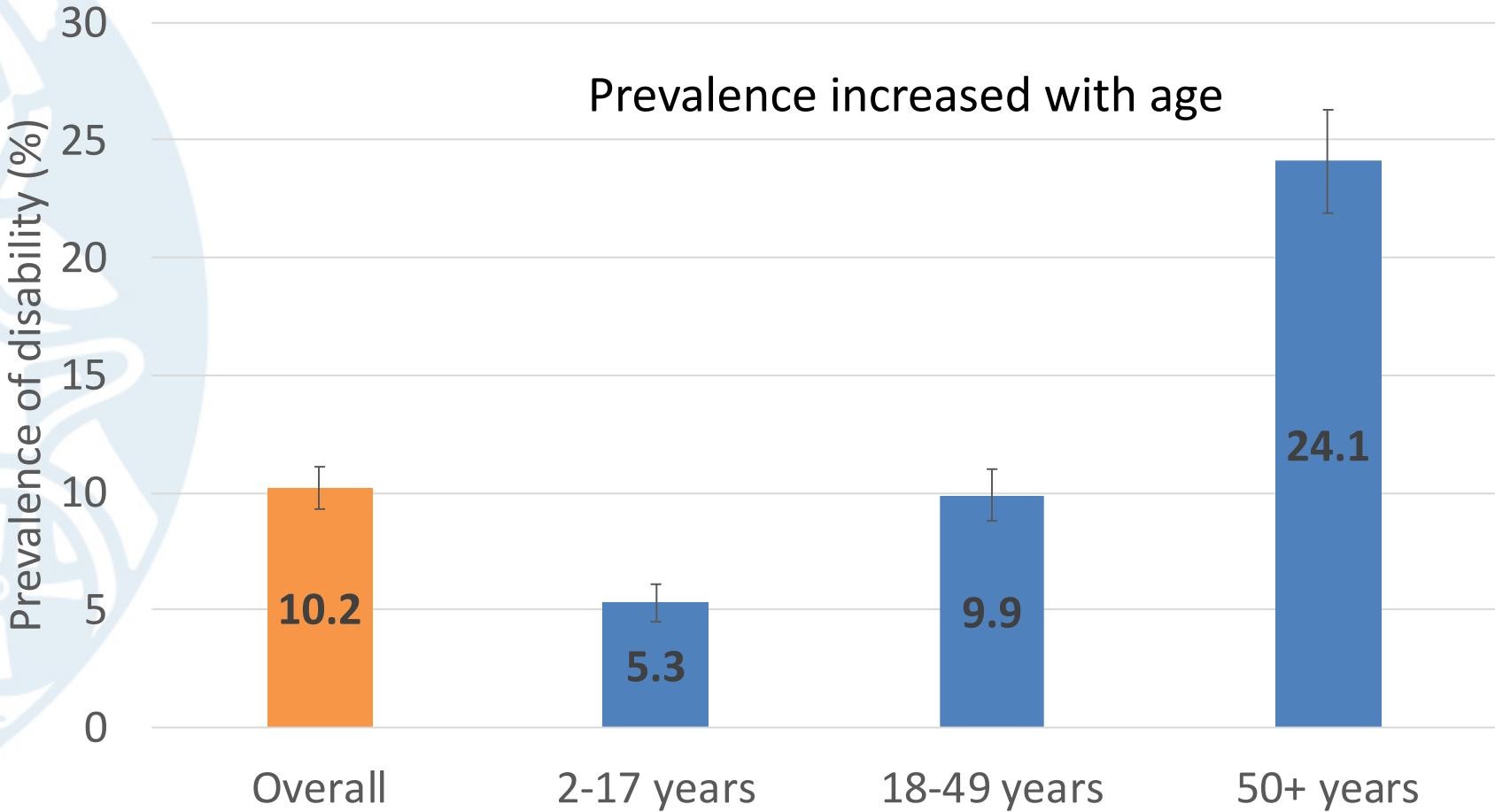
- Demographics
- Education
- Livelihoods
- Health and antenatal care
- Rehabilitation (people with disabilities only)
- Participation restrictions
- Environment
- Quality of life
- Water and Sanitation

Prevalence of disability

LONDON
SCHOOL of
HYGIENE &
TROPICAL
MEDICINE



13,073 people participated – response rate 88%

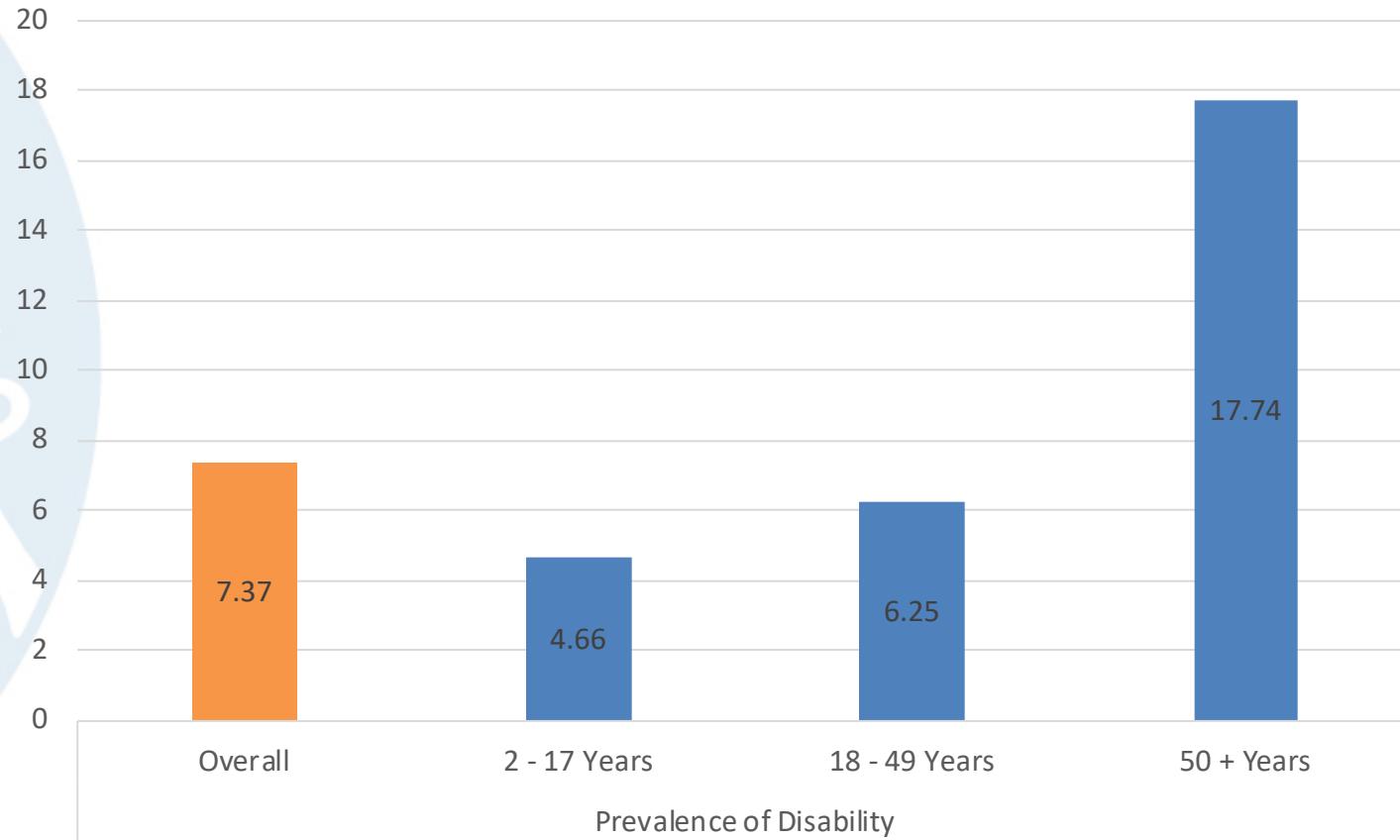


Prevalence of disability – Washington Group Only Results

LONDON
SCHOOL of
HYGIENE &
TROPICAL
MEDICINE



Washington Group Only Results – slightly lower

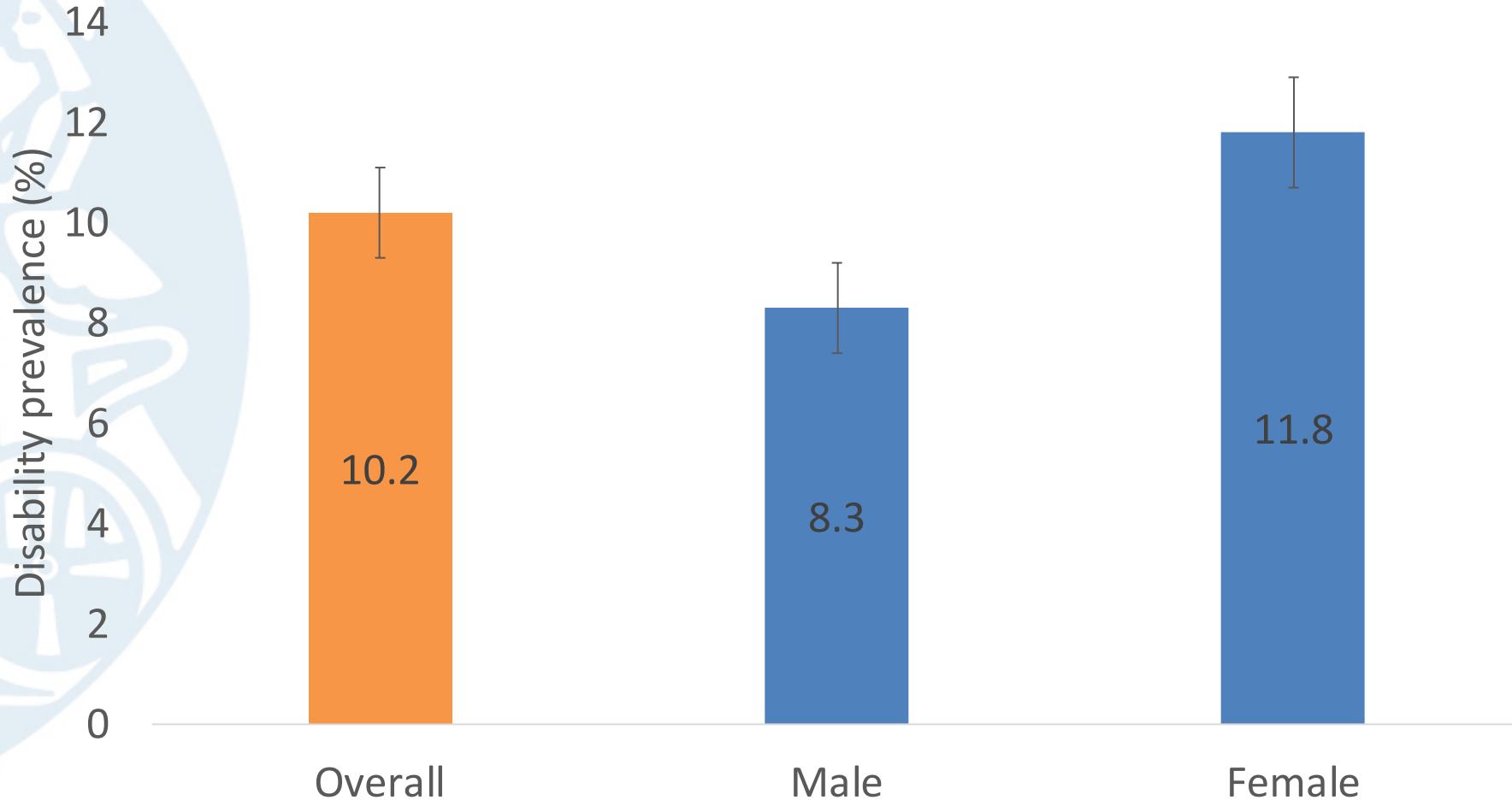


Prevalence of disability – results for men and women

LONDON
SCHOOL OF
HYGIENE &
TROPICAL
MEDICINE



Prevalence was higher among women than men



Households

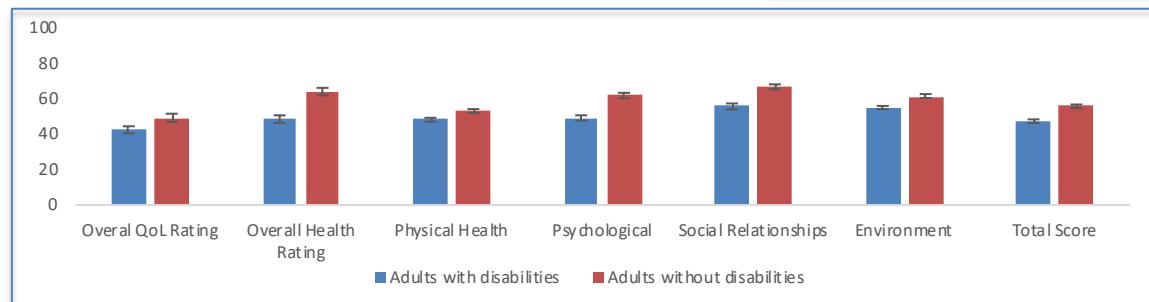
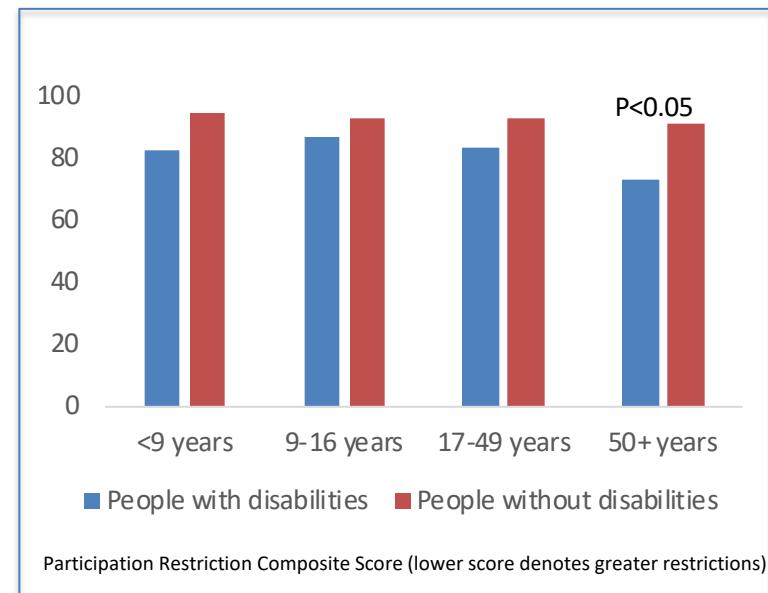
LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



- **31%** of households included at least one person with a disability
- Households including a person with a disability:
 - Larger household size and older average age
 - Greater dependency ratio
 - Lower proportion of people working

Individuals

- Children with disabilities were half as likely to have their biological father living at home compared to children without disabilities
- In rural areas, children with disabilities were less likely to be attending school (61%) compared to children without disabilities (82%). No difference in urban areas.
- Adults (18+) with disabilities were
 - less likely to work
 - more likely to do occasional work rather than regular work
- People with disabilities were less likely to:
 - be able to use the same toilet as other household members
 - use toilet facilities without assistance from others
- People with disabilities experienced greater participation restrictions and lower quality of life



Recommendations

- 1 in 10 people, and 1 in 3 households in Guatemala include at least one person with a disability
- People with disabilities in Guatemala and their families experience multiple disadvantages and exclusions, contrary to the UN CRPD
- To meet the goals of the SDA inclusion of people with disabilities must be made a priority
- Collection of comparable data on disability will support planning inclusive services and monitoring/evaluating their success