Guatemala National Disability Study (ENDIS 2016)

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

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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
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*

* Children only

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

* 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*

* Children only

Hearing Test using HearTest
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*

* Children only

Physical Performance Test using PPT
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*

* Children only

Age 18+ If ‘some difficulty’/ ‘a lot of difficulty’ or cannot do’  
Clinical Depression Test using PHQ9
• 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
13,073 people participated – response rate 88%

Prevalence of disability (%)

- Overall: 10.2%
- 2-17 years: 5.3%
- 18-49 years: 9.9%
- 50+ years: 24.1%

Prevalence increased with age
Prevalence of disability – Washington Group Only Results

Washington Group Only Results – slightly lower

<table>
<thead>
<tr>
<th>Prevalence of Disability</th>
<th>Overall</th>
<th>2 - 17 Years</th>
<th>18 - 49 Years</th>
<th>50 + Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (%)</td>
<td>7.37</td>
<td>4.66</td>
<td>6.25</td>
<td>17.74</td>
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</tbody>
</table>
Prevalence of disability – results for men and women

Prevalence was higher among women than men

<table>
<thead>
<tr>
<th>Category</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>10.2</td>
</tr>
<tr>
<td>Male</td>
<td>8.3</td>
</tr>
<tr>
<td>Female</td>
<td>11.8</td>
</tr>
</tbody>
</table>
Households

- 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
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